

BURROW, KENNETH A., M.S. *Disrupting Normal: Narratives of Inclusion in Mental Health and Aging*. (2009)  
Directed by Dr. Janice I. Wassel. 92 pp.

Throughout our nation's history, people who were older, mentally ill and developmentally disabled have been cared for in various types of settings. The nature and intensity of care has steadily evolved, from the almshouses of the eighteenth century to the poorhouses and county homes of the nineteenth and twentieth centuries, and finally, to modern assisted living communities of the present day.

In the late 1950s, my family entered the system of congregate care when my parents became the superintendents of the county home in Asheboro, North Carolina. All through my childhood I was entrenched in a world where we lived in the county home with the individuals who, for various reasons, had no other place to call home. While we did not realize it at the time, we were establishing an environment where abnormal did not exist, one in which people could live without the fear of being judged for being "different."

In addition to conveying the history of poorhouses and county homes, this study explores and puts into words the relationships I had with specific individuals while growing up in the county home.

DISRUPTING NORMAL: NARRATIVES OF INCLUSION  
IN MENTAL HEALTH AND AGING

by

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A Thesis Submitted to  
the Faculty of The Graduate School at  
The University of North Carolina at Greensboro  
in Partial Fulfillment  
of the Requirements for the Degree  
Master of Science

Greensboro  
2009

Approved by

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To Betsy, Sally, Simon, and Emma.

Thank you for making my life richer.

## APPROVAL PAGE

This thesis has been approved by the following committee of the Faculty of The Graduate School at The University of North Carolina at Greensboro.

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## ACKNOWLEDGMENTS

Firstly, I would like to thank my committee for assisting me throughout this endeavor. I would also like to thank Anita, my sister, for helping me with proofreading. Finally, I would like to thank my advisor, Dr. Janice I. Wassel, for her constant encouragement.

## PREFACE

Mary was my best friend when I was five years old. We did everything together. We played games, watched television, sang songs, colored in coloring books, and ate practically every meal side by side. Actually Mary lived with us throughout most of my childhood. In 1969, when many other children were starting kindergarten, I didn't attend, so Mary and I had plenty of time to entertain each other. Mary was smarter than me. She taught me how to count all the way to 100, and she helped me learn to recite the entire alphabet. Mary didn't have much to say to anyone other than me. She was very quiet and kept to herself when I wasn't around. I was an adult before I realized that our relationship was not what most people would consider normal. And as I think about it now, depending on your definition of normal, I guess they would have a good point, since Mary was 62 years old when I was five.

Growing up in the county home and family care home that my parents operated, I had an upbringing that was unlike most other children of the 1960s and 70s. My relationship with Mary is one of many life experiences that launched the framework for this thesis, and invites the question, "Can the boundaries between clinically normal and abnormal, as constructed by American society, be disrupted?"

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## CHAPTER I

### METHODOLOGY

#### Methods

Using a post-modern epistemology, and qualitative methodology, this study addressed the question, “Can the boundaries between clinically normal and abnormal, as constructed by American society, be disrupted?”

*Qualitative research is inherently multi-method in focus. However the use of multiple methods, or triangulation, reflects an attempt to secure an in-depth understanding of the phenomenon in question. Objective reality can never be captured. We know a thing only through its representations. Triangulation is not a tool or a strategy of validation, but an alternative to validation. The combination of multiple methodological practices, empirical materials, perspectives, and observers in a single study is best understood, then, as a strategy that adds rigor, breadth, complexity, richness, and depth to any inquiry. (Denzin & Lincoln, 2005)*

Quantitative research has been likened to a map (May, 2002). It shows the user exactly where a specific “place” is located and how close it is to other places. In contrast, qualitative research is akin to a video. While we cannot necessarily discern the location by viewing the video, we can gain an understanding of the location by observing the surroundings, the people who are included in the video and the actions of those people. Qualitative research is a competent tool for investigating a topic or subject matter that has not previously been explored. The researcher often approaches a topic without having established preconceived ideas of the outcome. The theory is built as the “story” is

revealed (Camic, 2003). Because of my unique perspectives as a participant in my own study, I assert that the qualitative approach best demonstrates possibilities for blurring clinical boundaries.

The following methods were used for this study:

### ***Historical Research***

Through review of a broad range of documents, I employed historical research, specifically the history of poorhouses and county homes, and the mental health records of the people included in the case studies section. The past is the historical researcher's database. This database often consists of birth and death records, ships' logs and church records, and helps to determine the roles that various people played in their communities. The exploration of these historical documents can explain relationships, provide answers to queries, lead to additional questions, and/or supply additional concepts/ideas that warrant further investigation (Salkind, 2006).

Historical researchers typically depend on primary and secondary research (Salkind, 2006). This primary data collection used included birth and death certificates, minutes of meetings, photographs, newspaper accounts, oral histories, and mental health records of people who lived in the county home and family care home where I lived as a child and into my adulthood. Also, included in this study were secondary sources of data, including state and county reports (county home demographics, county home pamphlets, correspondence between state and county officials, and social services reports). Furthermore, the history of providing care for North Carolina citizens who were indigent, including those who resided in poorhouses, county homes and family care homes was

included. The information collected and analyzed came from the North Carolina Office of Archives and History, the Randolph County Register of Deeds, Randolph Public Library, and my family's personal documents. While reviewing these multiple forms of documentation, I examined and observed how they complement the story. These observations are included throughout the thesis.

### *Case Studies*

In the process of conducting qualitative research, one method that can be employed is the use of case studies. Case studies 'examine the bounded system of a program, an institution or a population' (Marshall & Rossman, 1989, p. 41), while allowing the researcher to expose the uniqueness of the group being studied (May, 2002). Specific chapters of this thesis use the method of reviewing case studies. I produced case studies of people who lived with my family either in the county home or family care home with my family (all names are pseudonyms). When we review case studies retrospectively, we may see things differently, and in the end, change the interpretation of the events that occurred (Camic, 2003). Though using case studies as a mode of research may present risks of generalizing topics or cohorts, it sometimes presents itself as the only method to scrutinize and/or study specific avenues (Willig, 2008). Case studies/reports communicate experiential learning, which may add to the reader's experience by making use of "narratives and situational descriptions of case activity, personal relationship, and group interpretation" (Stake, 2005).

In this study, I used a very straightforward approach for case studies, which examine three questions.

1. Which people provide the most profound memories for me?
2. Of those people, whose life stories would be of interest to the reader?
3. Whose mental health records could I successfully access?

### ***Narratives, Life Stories, and Historical Memories***

While validation of qualitative research rarely takes on the same format as that of quantitative research, the qualitative researcher must nonetheless be able to justify the study at hand (Crossley, 2007). With narrative research, the researcher is expected to provide support for his/her inquiries by constructing lines of reasoning and offering evidence which, rather than delivering certainty as to an outcome, in essence, produces a *likelihood* as to the soundness of the argument (Crossley, 2007). Through the use of narratives, people provide accounts of their lives, the events that have occurred during their lives, and how they (the storytellers) connect with others (Maynes, Pierce, 2008). Narratives may be extracted during an ordinary conversation, as a part of fieldwork, or during a formal interview process. Narratives may be complete in details, or disjointed, only telling a portion of the life story, yet giving enough detail to convey the important aspects of the story. Oral and/or written narrative formats are acceptable modes of gathering information (Chase, 2005). Narratives help us figure out the world around us by supplying the structure that we use to build our personal stories, which in essence helps form our personal identities (May, 2002).

One of the most frequently accepted ways to share personal narratives is through an autobiographical process (Crossley, 2007). Through this type of communication, one can follow a succinct process whereby the storyteller is able to convey key events in

his/her life, and share information about people whom he/she considers to be an integral part of the story, while at the same time weaving a narrative from which the reader can discover and dissect the life story (Crossley, 2007).

The narratives for this study are stories from my past. More importantly, they are stories of the people who lived with me from my earliest years; they are people who found themselves, for various reasons, living as indigents. An added component to the stories is how my life intertwined with their lives, thus creating a combined chronicle of our passage through life. This passage was for me, as a child, and for them, as marginalized adults. Through retrospective documentation of various events, I recorded my memories and the life stories of individuals, now deceased, but who once lived in the county home and in the family care home that my parents operated. I shared a narrative account of these memories and events, which I witnessed as a child and a young adult.

### **Data Collection**

#### ***Artifacts/documents/records***

It is important that the historical researcher validate and assure the authenticity of the data that is used (Salkind, 2006). The data used in this study meets these standards. In addition to sources from the Randolph Public Library and the North Carolina State Archives, I located archived medical/mental health records from Sandhills Mental Health Center, Dorothea Dix Hospital, John Umstead Hospital and Broughton Hospital. These records include psychiatric assessments, social histories, admission assessments, medication evaluations and psychological testing. I reviewed this information to

determine the documented causes for which these individuals sought psychiatric care, the diagnoses they received while receiving that care, and the treatment methods used.

### **Data Analysis**

#### ***Textual Analysis and Reflexivity***

For this study, I did not assume any predetermined analytical approach of the aforementioned written materials; rather, I attempted to identify fundamental themes, thus illustrating the personal and cultural world of which the text/material is a small part.

Perakyla (2005) supports this method of text analysis.

*An informal approach may, in many cases, be the best choice as a method in research focusing on written texts. Especially in research designs where the qualitative text analysis is not at the core of the research but instead is in a subsidiary or complementary role, no more sophisticated text analytical methods may be needed.*



## **CHAPTER II**

### **POORHOUSE ORIGINS**

Since the early days of our nation, a portion of indigent and disabled citizens have been cared for by non-family members, a practice that can be traced to our ancestors in England. After centuries of attempting to deal with problems stemming from pauperism, the British instituted taxation in 1572 specific to alleviating some of the suffering of the poor. Overseers of the poor, a group of men who were typically appointed by the local justice of the peace, were responsible for administering the funds that were garnered through taxes (Brown, 1928).

The English Poor Law, which was established during Queen Elizabeth's reign, divided the poor into three categories or classes: those who were considered able-bodied, the helpless poor, and children. These groups were managed in distinct fashions. Children were apprenticed, which meant living with and being supported by a tradesman who could teach the child a trade, thus decreasing the likelihood that the child would become a dependent adult. The impotent poor were cared for in almshouses, settings that offered little more than shelter. The able-bodied were dealt with in quite a different manner. They were rounded up and returned to their birthplace or the village in which they had last lived for one year or longer. During this same era, workhouses were created, settings in which the poor were expected to provide labor in exchange for the shelter and food they received (Brown, 1928).

Another custom that originated in England was the practice of auctioning off the care of the poor to the lowest bidder who was paid with local tax dollars and had the responsibility of providing care for the person(s). Auctioning to the lowest bidder was an obvious attempt to ensure frugality with public funds (Wagner, 2005).

The policies and laws that were established in England followed settlers to the new colonies. As early as 1749, a bill for the “relief of the poor and the prevention of idleness” was introduced in the North Carolina colonial assembly (Brown, 1928). The subsequent laws that were enacted over the next several years closely resembled the laws that had been followed in England. In 1785, the first almshouses in North Carolina were funded when the legislature ratified a law that gave authorization for overseers of the poor in Carteret, Chowan, Halifax, Nash, Northampton, Onslow, and Wayne counties to purchase land and administer the erection of almshouses. The law stated “persons being either distracted or otherwise deprived of their senses, so that the wardens shall judge them incapable of self-preservation, shall be under the care of said wardens, who are empowered to keep them confined in such houses so long as they may judge necessary” (Brown, 1928). Between 1793 and 1830 several more laws were enacted which gave specific counties permission to secure land and establish poorhouses. The objective for purchasing large tracts of land on which the poorhouses would be constructed was simple. It was expected that the counties would ensure the production of crops on the land in order to feed those who resided in the poorhouses (Brown, 1928).

Similar to the almshouses in England, poorhouses throughout the nation were typically used to provide care for extremely diverse groups of people: the elderly who did

not have adult children who could care for them and could no longer provide for themselves, children who were orphaned, widows and children, people with mental illness, usually referred to as “the insane,” and still others with developmental disabilities, or “the feeble-minded,” a term that was used well into the twentieth century (Wagner, 2005).

During the middle part of the nineteenth century, Dorothea Dix, an activist who championed the rights of people with mental illness, came to North Carolina and surveyed the state’s poorhouses and jails in an effort to call attention to the need for better care for people who were considered insane and lived in these settings. In a report that she prepared for the North Carolina House of Commons, Dix concluded that the poorhouses throughout the state were unsuitable settings in which care should be provided for people with mental illness. One statement reads, “If jails are unfit institutions for the treatment and restraint of the insane, county poorhouses are but a degree, if at all, more suitable” (Gollaher, 1995, pp. 145). During her stay in North Carolina, Dix was instrumental in convincing the state’s lawmakers to improve the care that was provided for people with mental illness. By touring the county homes and jails, preparing reports on the conditions, and lobbying for reform, Dix was successful in persuading the lawmakers to establish a state asylum for the insane. The hospital was completed in 1856 on a site that the state legislature designated as “Dix Hill” (Gollaher, 1995). Although advocates such as Dix were successful in bringing attention to the needs of the people with mental illness and the establishment of state mental hospitals, the

majority of the institutionalized people with mental illness languished in poorhouses throughout the nineteenth century (Katz, 1984).

The state of North Carolina began reporting statistics and narrative information related to the care of its indigent population when it published the *First Annual Report of the Board of Public Charities* in February 1870. This 125-page document was requested by the General Assembly as a means for gathering data about the county poorhouses and penal institutions. Additional information was obtained about state institutions, the “insane asylum,” and the “deaf and dumb and the blind” institution, a setting for children. The report confirms that varying groups of people were cared for in the poorhouses. One passage of the report states:

The County Alms-houses are also an institution of the olden time, and very properly called “Poor Houses.” These are the receptacle of the infirm, aged and diseased who are destitute or cast off by unnatural or equally poor kindred, the orphan and the child of poverty, for whom beats no heart warm with the kindly emotions. Here is almost equal banishment from the presence of human love and care, as in the case of the prisons. The respectable, aged and infirm pauper is shut up with the worn out strumpet, whose very presence is pollution, and no care is had, in many cases, for the innocence of childhood (*First Annual Report of the Board of Public Charities of North Carolina*, February 1870, pp. 7).

The information that was collected for the purpose of preparing the report was obtained from the local governments who operated the jails and poorhouses. A circular with a series of 34 questions was sent to each county. Questions covered a variety of areas, including construction of the buildings, land use, and punishment given to inmates. The poorhouses and penal institutions were lumped into the same category within the report. Responses were received by the Board of Public Charities from 71 of the 100

counties in the state. The number of inmates in the poorhouses ranged from one in both Haywood and Moore counties to 66 in Guilford County. Additional statistics that were published in the report included the number of inmates who could be accommodated in each poorhouse, the number of the inmates who were capable of working, and the number who were considered helpless. The final section of the report provided data related to the number of inmates in the state's poorhouses who were insane (37), and the total who were idiotic (90). Nowhere in the report is there a breakdown of the ages of the people living in the poorhouses (*First Annual Report of the Board of Public Charities of North Carolina*, 1870).

By the early part of the twentieth century, North Carolina's poorhouses were evolving into county homes, and the types of services had started to change. The *Annual Report of the Board of Public Charities of North Carolina; 1908* indicated that conditions varied greatly in county homes across the state. The Burke County report states:

The building is new and comfortable. Now in charge, 28. Two insane epileptics. None confined. Plenty of good, wholesome food. The Superintendent receives \$5.25 per capita and the proceed of the farm. He is a good man for the place. Physician is Dr. J.L. Laxton, Morganton, paid \$3 per visit. Admitted in six months, 2. No deaths. The sick are well cared for. Have a nurse when necessary. One hundred and one acres, generally very poor land; 25 or 30 in cultivation. Corn, wheat and vegetables raised. Religious services monthly. Three idiot children, one white and two colored (*Annual Report of the Board of Public Charities of North Carolina; 1908*, pp. 87).

Within the report is a letter from Dr. Laxton:

The inmates are mostly epileptics, paralytics and idiots. Three of the latter—altogether the most helpless set of mortals to be found, according to number. The inmates are well cared for and the Home is in fine sanitary condition. Rooms are

clean, beds and bedding and nice iron bedsteads. All precautions have been taken to prevent epileptics from falling into the fire, by iron bars properly placed in front of the fireplaces. Grove and grounds are kept clean and some of the women raise flowers which look quite showy along the borders and seem to give much pleasure in the looking after them. The keeper is the right man in the right place. Good, pure well water (*Annual Report of the Board of Public Charities of North Carolina; 1908*, pp. 88).

The findings of the county home for Jones County were quite different:

The Home is in the woods two miles from the county seat. One frame building of eight rooms, pantry and hall; one log building with two rooms. Ventilated by windows. No fire protection. Open well. Fireplaces. Can accommodate 20 or more. Now in charge, 2. No insane or epileptic. No superintendent. Physician is Dr. W.W. Early, Trenton; salary, \$50 per year for one visit per month; other visits extra pay. Died, 2. There is no attendant. Those sick are cared for by the other inmates. Premises in fair condition. The house is new. Kitchen in fair condition. One acre used as a vegetable garden. Shaded. Preachers go out to see the inmates several times a year. No children. Remarks: The County Home is in fair condition. The inmates are treated fairly well. Every Christmas the ladies of the town go out and carry nice things to eat, clothes, etc. They also have some preacher to attend on this day (*Annual Report of the Board of Public Charities of North Carolina; 1908*, pp. 101).

The report also lists laws that were passed within the reporting year. One law was related to funding for the erection of new homes/buildings in four counties, while another law made provisions for counties to utilize prisoners at the county homes and county farms. The law stated, “Warren to work all misdemeanants for terms of less than two years on the county farm. Caswell to work on county farm. Columbus and Randolph to hire out or use for County Home” (*Annual Report of the Board of Public Charities of North Carolina, 1908*, p. 209). Prisoners who were sentenced to work on the county farm and/or at the county home were in essence a form of free labor. Justices of the peace or judges could sentence people (male and female) to the county home/farm for periods of

up to two years. The prisoners were expected to assist in any way the superintendent deemed necessary. This included tending gardens, cooking, cleaning, and even assisting with non-prisoner inmates who could not care for themselves. The prisoners would be allowed to go about their daily tasks unrestrained; however, in many instances, they were locked up in a room or separate building come nightfall (Brown, 1928).

In 1928, thirty-nine counties in North Carolina reported having a total of 79 children as inmates of the county homes, half of them being labeled as “feebleminded.” Fifty-three percent of these children were under the age of six. Forty-two of the children were born in a county home. In two cases, the former superintendent of the county home was believed to be the father of the child. An additional eight boys were serving sentences as juvenile delinquents in three separate county homes (Brown, 1928).

According to a survey that was conducted by Dr. Harry W. Crane in 1922, there were approximately 700 people living in county homes in North Carolina who were considered feebleminded. An additional 300 people who were identified as insane lived in county homes during this same time. Fifty-five of these people were “forcibly confined in their rooms or in cells” (Brown, 1928).

Forms of discipline were administered in many county homes throughout North Carolina. The discipline ranged from forcing the individuals to perform work chores to locking them in cells. Superintendents served as “judge, jury and jailer” (Brown, 1928). During a visit to a county home in the mid 1920s, a caller found an older woman who was confined to a cell. Upon investigation, it was determined that she had been sentenced

to one week in the cell for failing to milk the cows, her daily assigned task (Brown, 1928).

In the late 1930s, the state of North Carolina was attempting to transition its county homes. As the Social Security program came about, it became prudent for counties to serve people outside of the county home settings. Social Security funds could not be utilized for people who lived in county operated settings; therefore, the cost of operating the county homes and providing care for the people who lived there fell entirely on the county. In order to take advantage of federal funds (Social Security) North Carolina began exploring the possibility of serving people in other settings (Nygard, 1938). A survey of county homes in North Carolina revealed that there were 85 county homes in operation. The average per capita monthly cost was \$17.29 (Nygard, 1938). The report also suggests that county homes were beginning to be “depopulated” as a result of Old Age Assistance.

Over the next few decades, county homes steadily faded away. By the early 1960s, the majority of the county homes in North Carolina had closed or been converted to licensed rest homes. In January 1962 a special study, *Leasing of County Homes in North Carolina*, was published by the Institute of Government, The University of North Carolina Chapel Hill. This 56-page document provided information for county governments related to the leasing of county homes to private individuals. Some of the topics that were covered included eligibility for public assistance, estimated monetary savings to the county, and selection of the lessee. A sample lease agreement was also provided for each county to use as a template if they so chose.



Over the past few decades, North Carolina's licensed facilities have continued to operate and provide services and supports for people who are older, mentally ill and/or developmentally disabled. The terms used to describe these settings have evolved during this same period of time (rest homes, homes for the aged, domiciliary care homes, family care homes, adult care homes, assisted living facilities and assisted living communities). Today, the range of settings and services vary greatly; however, each setting, regardless of its lavishness or lack thereof, can trace its roots to the poorhouses and county homes that were created over a century ago.

### **CHAPTER III**

#### **BACKGROUND ON THE POORHOUSE IN RANDOLPH COUNTY**

Like the majority of counties in North Carolina in the late 1800s, Randolph County provided care for its indigent citizens in a poorhouse setting. The poorhouse (also referred to as the poor farm) was located in the central part of the county on a few hundred acres in an area that is now known as Caraway Mountain. The inmates who called this setting “home” were all ages. Some of the inmates were elderly, with no place to go and with no family to care for them. Others were people with disabilities and/or mental illnesses, either abandoned by family members or had no family members to provide them care. Often, children who were orphaned ended up living at the poorhouse. In addition to these groups of people, there were also infants who were born at the county home (*Asheboro Courier*, 1943).

While the land that the Randolph County poorhouse was located on was spacious, the housing itself was quite minimalistic. There were three houses, which were little more than shacks; one had bars over the windows. Young and old, disabled and able-bodied, black and white all lived together in these shacks. Like most other poorhouses across the state, the inmates who were capable took care of the land and animals and grew the food necessary to provide their sustenance. Those inmates who were incapable of providing their own care were tended to by the other inmates (Kessler, 1999).

In the early 1920s, like many other counties throughout the state, Randolph County began the planning for a new poorhouse, by this time referred to as the county home. Approximately 200 acres was purchased two miles south of the center of Asheboro, the county seat. On this property was erected a state of the art facility that was 12,400 square feet in size. Total cost for the land and the building was approximately \$43,600. In May of 1922, all of the inhabitants of the old poorhouse moved to the new county home on South Fayetteville Street (*Asheboro Courier*, June 8, 1922). For the next 35 years, inmates lived in the county home under the supervision of various superintendents and continued to provide care for one another and tending the farm.

### **Moving to the County Home**

In the late 1950s, my family became involved with providing care for people who were indigent when my mother and father learned about an opening for someone to operate the county home. A neighbor had mentioned to them that the county would soon need a new superintendent and a matron; as a relative of his, who was the current superintendent, was leaving the position after several years. Soon thereafter, the county commissioners approached Mama and Daddy about taking over the operation of the home. My daddy prayed about this new opportunity for several days. A spiritual man, he never made decisions without asking God for guidance. After much thought and prayer, and a great deal of discussion with Mama, he decided that they should apply for the positions. While he knew this opportunity would create a change in direction for the family, I don't think he had a true sense of how the decision would alter their lives, the lives of their children, grandchildren and great-grandchildren, along with thousands of

people for whom services would be provided over the next several decades. At the time, there were few rules or regulations regarding managerial experience or educational requirements for the superintendent of a county home. Because my parents had experience raising a large family, my mother was a good cook, and both of them were well thought of in the community, they were hired.

My parents grew up very poor; although, as they told me on several occasions, neither of them realized it at the time. My mother was the second child in a family of 14 children. From the time she was six years old, she was looking after her younger siblings, doing chores around the house, and working in the fields. Mama was nine years old at the beginning of the Great Depression, but day-to-day life continued on as usual for her family. They had no stocks to lose, no vehicles to drive, and no money to purchase niceties. The food they ate came from the vegetables they grew and the animals my grandfather raised. My father's upbringing was somewhat different, though just as impoverished as my mother's. While Mama grew up on a farm, Daddy grew up in the small town of Franklinville. He had two siblings, younger sister Valney, who died at the age of three, and older brother Virgil, with whom Daddy remained very close throughout their lives. Daddy's mother died when he was twelve years old, leaving a big void in his sensitive, young heart. His father, John Clayton Burrow, was a cotton mill worker who didn't show a lot of emotion to his children. He remarried soon after my grandmother's death, but Daddy's bond with his stepmother was short-lived, as she too died while Daddy was in his teens.

Mama and Daddy met when she was 14 and he was 21. Grandpa (Mama's father) made them wait to get married. Grandpa sent Daddy away because he was not a Christian and told him that he could see Mama after he became a Christian. They married soon after Mama turned 18, and a little over nine months later Mama gave birth to a nearly full-term stillborn baby. My oldest brother, Clayton, was born about a year afterwards. A couple of years later, my oldest sister Lou was born. Mama, Daddy, Clayton, Lou and Daddy's father lived several years in an old schoolhouse that they rented. Mama worked in the cotton mill while Daddy worked at a saw mill and as a carpenter. Grandpa John, who had mellowed in his later years, stayed home and took care of Clayton and Lou. In 1948, Mama gave birth to Emma Jean, who lived for only one day. A few months later, Grandpa John also died. During this time, my parents barely had enough money to get by, but they made certain the children had food to eat and shelter. Daddy built a new house in the late 1940s, but it was quite modest, with only one bedroom, a kitchen, and a living area which doubled as a bedroom for Clayton and Lou. Three more children were born over the next several years, Anita in 1950, David in 1954, and John in 1957. When John was one year old, the entire family, with the exception of Clayton who had recently gotten married, moved into the county home.

Moving into the county home was literally a step up for my family. Here, for the first time, they had indoor plumbing. Although Daddy had built the shell of a bathroom in their last house, he never had the opportunity or the money to install plumbing. The family was also able to watch television, something they had never had the privilege to do, as they never owned one. With the "pleasantries" that came with moving into the

county home came the temporary culture shock (at least for the children) of living with over 50 people, some of whom were severely disabled.

### **Inmates of the County Home**

Jake was one of the first persons my siblings saw the day they moved into the county home. He had lived there for several years and was unable to use his legs, which were extremely malformed. He pushed himself around on a board with wheels that someone had made for him. Another gentleman, Billy, had come to live at the county home when he was an infant. According to my mother and father, Billy had been found abandoned in the woods by hunters who brought him to the county home in the 1920s because there was nowhere else for him to live. Billy was considered severely mentally retarded and was able to speak only a few words. His favorite pastime was to run down to the train track in front of the county home each time he heard the train approach and the engineer would throw candy to him. This ritual continued well after we arrived at the facility.

When Mama and Daddy became the superintendent and matron, there were two inmates, Ross and Dora, who served as surrogate parents to all of the other inmates. There were two separate wings, the north side and the south side, better known as the women's side and the men's side. At that time, men and women were not allowed to mingle. Ross served as the father to all of the men, and Dora as the mother to all of the women. All of the other inmates went to them when they had unmet needs or required guidance. Ross and Dora also tended the personal care needs of the people who were severely developmentally or physically disabled. While I don't remember Ross, as he had

either moved or was deceased prior to my birth, I remember Dora quite well. She lived until the early 1980s and continued to care for one specific individual, a lady named Ronnie Mae who had Downs Syndrome and could articulate one word, "Mama." In all of the group pictures that were taken over the years, from before we moved to the county home until just before Dora's death, Ronnie Mae is close by Dora, her "mama." Ronnie Mae grieved terribly after Dora's sudden death. She had no way of understanding where her mama had gone. Nine months later, Ronnie Mae passed away. I have always believed that she died of a broken heart.

Ethel and Lucille, two sisters with mental retardation, also lived at the county home when we moved there. Prior to moving to the county home, both of them lived in a little town in the eastern part of the county where they were prostitutes. Men in the area would take advantage of them by offering a meager amount of money in exchange for sexual favors. After moving into the county home, Lucille took on the responsibility of going to the curb market, which was just down the road, for all of the other inmates. She would take orders from everyone in the building, taking a dollar from one person, five dollars from another, and change from others, go to the curb market without writing down one item (she could not write), and come back with everything that had been requested, and each person's exact change.

Tom also lived at the county home when we arrived. Tom had a congenital disability which made it impossible for him to speak clearly, but that never stopped him from getting his point across. By using gestures and grunts, he would communicate until he made you understand what he was saying. Tom was the "keeper of the doors." Before

he went to bed each night, he would walk around to every door in the building and ensure each one was locked. This tradition continued until we moved out of the county home in 1990 and into a new assisted living facility, Brookstone Haven, which is in Randleman, a town north of Asheboro. In the new building, he continued his tradition of checking all of the doors at night. He didn't stop checking the doors and ensuring everyone was safe until his death in the mid 1990s. Tom was the last survivor of the county homes days. Our family mourned deeply when he passed away. One of our family members had died, and it left a terribly empty space for all of us, as most of us had known him our entire lives.

Wiley was also an inmate of the county home when we arrived there. He was a very meek and mild man who rarely spoke and most likely had mild mental retardation. As Mama and Daddy were so busy getting the facility into order, Wiley took on the role of babysitter for John, who was at that time one year old. Over the next few years, Wiley would play with John to entertain him. It was not at all uncommon to see Wiley pulling John around in a little red wagon, doing his best to make sure John was happy and content. One of John's first words was, "Iley." Lucille was Wiley's girlfriend, and when Wiley was not entertaining John, he was entertaining Lucille, usually in the basement where no one was privy to their mischief.

### **Creating a New Home and Family in an Institutional Setting**

One of Mama and Daddy's first goals was to clean the building. My sister Lou has told me several times about their first night at the county home. Our family lived upstairs in the apartment. Down the steps of the apartment, you turned a corner at the



bottom and walked directly into the kitchen. Lou came downstairs that first night, turned the corner and flipped the light switch. The entire kitchen looked black, but she quickly realized the room was swarming with roaches. In addition to the roaches in the kitchen, the remainder of the building was filthy. There was dust that appeared to be nearly an inch thick coating everything. The bathrooms looked like they had not been cleaned in years. The floors were so dirty that you couldn't see the true color or patterns. Inmates' clothes were hung on nails in the walls, since there were no closets in the building.

Although the inmates had done their best to take care of each other, they were just as dirty. Mama and Daddy worked tirelessly for several months to clean the building and the inmates. They made the county home a place where even those who were indigent and had no other place to call home could live in a sanitary environment.

Another goal for Mama and Daddy was to make the county home as homelike as possible. Most of the inmates had no family (or at least none who would visit them), so Mama and Daddy set out to give them the home they had never had. In order to accomplish this goal, they felt it was necessary to "blend" our families. Each Easter there would be Easter egg hunts for the inmates and us, the children. Christmas trees were set up in the main living rooms where we would celebrate our Christmas mornings with the inmates. My sister Anita told me about going downstairs in the inmates' living room and watching television with them. She would dance to the music of *Hullabaloo*, a musical variety show, as the inmates looked on and enjoyed having the energy of a teenager in their midst.

Three years after moving into the county home, the Randolph County commissioners converted the building into a rest home (Randolph Rest Home), and leased it to my parents to operate. For the first four years of my life, I lived in the rest home with my parents and three of my siblings. Lou had married by this time. In 1968, my parents moved out of the county home with their four youngest children (Anita, David, John and me), and my sister Lou and her family took our place living there and operating the facility as a rest home. Although I was only four years old when we moved, I do have memories of living in the county home/rest home. I remember running down the long halls into the arms of patients (they were no longer known as inmates). I remember playing with my brothers on the swing-set that was in the front yard....the front yard of a rest home. I remember eating biscuits made by Mama's older sister, Opal. (Aunt Opal was the cook at the rest home. She and her husband Henry now live in one of the assisted living communities that my family operates. She is 91 years old and Uncle Henry is 94.) But most of all, I remember the family atmosphere created by my parents. I was born after Mama and Daddy moved to the county home. I knew no other life. In my eyes, the people who lived there were simply my grandmothers, grandfathers, brothers and sisters. I knew no different.

After we moved from the county home, the house we moved into was licensed as a family care home. There we lived with many of the same people who had previously been inmates of the county home and others who were deinstitutionalized from state psychiatric hospitals.

### **Not the Average Family**

It wasn't until I was much older that I realized that our "family" was not the average family. While many people have eccentric relatives who live with them at one time or another, most folks don't have a houseful of family members who've spent the majority of their lives in state institutions.

My earliest memories of living in the family care home are of interacting with the older ladies who lived with us. Living as one big family meant we went to church together, ate meals together, worked around the house together, and played games together; we did everything that "normal" families do. Mama and Daddy were both older by the time I was born (she was 44 and he was 51) so this added to my perception of what was normalcy.

Mama, a strict disciplinary, didn't mind enforcing her rules on her children or the residents who lived in the family care home. She expected us to do our share to support the family, including working in the garden, washing dishes, sweeping floors and helping with yard work. As I grew older, my role started to change.

### **My Changing Role in the Family Home**

Mama made me the intermediary at a very early age. "Go tell the ladies it's time to eat." "Tell Betsy it's time to get up." "Don't forget to give the ladies their medicine at eight o'clock." When Mama and Daddy went to church on Sunday nights, I was in charge of the home including administering the residents' medications. I'd pull a chair over to the medicine cabinet that was hanging in the hallway, climb on the chair to reach the key on the cabinet's top then unlock it, get out the medicine, give everyone their medicine,

lock it up and replace the key. Interestingly, I can still remember many of the drugs I gave them – Mellaril, Thorazine, Navane....some of the early psychotropic drugs.

I was always very conscientious to make sure people took the right medication. At that time, no one documented that the medicine had been administered (no MARs – Medication Administration Records), so there was no need to worry about a 10 year old's signature or initials showing up in a medical record (which didn't exist either). Mama would tell me to call the church if anyone stopped by or there was a problem. I guess that was our version of a crisis/emergency plan. But I don't remember ever needing to call her.

As time passed, the length of time that I was left alone with the ladies increased. By the time I was 16 years old and had started driving, I took on the responsibility of taking the ladies to their doctor appointments. I didn't mind any of these responsibilities. In fact, I enjoyed ensuring all of the residents received the care that they deserved.

Throughout the remainder of my childhood and adolescence, I lived with my parents in the family care home. When I turned 18 and graduated from high school, I enrolled at the local community college located less than a mile from the county home where I lived the first four years of my life. My sister was still operating the home as a licensed rest home. So I moved into the apartment upstairs where I had lived as an infant. While attending the community college, I worked part-time at the rest home, first in housekeeping for several months, and quickly moving on to being a personal care aide. In that capacity, I would bathe the residents, wash and comb their hair, shave the men, assist the residents with toileting and eating, and make certain they were dressed for the day.

With 31 residents in the building and typically two aides on first shift, there were a lot of baths to give to both men and women. The ladies quickly learned to trust me. Respecting their privacy, I would make sure they had a towel to cover their private areas, and while I would help them with their faces, legs, feet and backs, I would lather the washcloth and turn my back as they washed their private areas.

After working as a personal care aide for approximately a year, I was trained as a medication aide (although I had already been doing this as a child). Here I was responsible for administering medication three times daily to all of the residents, maintaining all medication orders, taking the residents to doctors, documenting in their charts, and communicating with physicians when the residents had ailments that needed attention. A year later I became a Supervisor-in-Charge (SIC) and in addition to my other duties, was responsible for supervising all personal care aides. By the age of 23, I became the live-in manager in charge of the entire facility, and continuing to live in the apartment.

One of the most critical aspects of my job was “knowing” the people who lived at the rest home. Over the years, I’ve frequently heard other professionals speak to the inappropriateness of becoming personally involved with the people to whom you provide care; however, when you are living with those people it is impossible to not become involved in their lives. You feel for those who have no families and you want to be someone they can trust and on whom they can depend. Perhaps knowing and becoming personally involved with those in your care makes you more compassionate and understanding, not only to the residents but to others as well.

Many of the people who we provided care for had mental health diagnoses and it was important for me to learn about the various types of mental illnesses. We provided support for people with schizophrenia, major depression, bipolar disorder, etc. and part of my job was to monitor the symptoms associated with their mental illness. I needed to know when someone with bipolar was showing subtle signs of manic behavior so I could contact the psychiatrist for a medication adjustment. I needed to ascertain when someone with depression who was refusing to eat meals or not sleeping well so appropriate treatment could be provided by their mental health professional. It was essential for me to realize if someone with schizophrenia was having delusions or showing signs that he/she was hallucinating. I continued to live at Randolph Rest Home until at 27 years old I moved away and into an apartment where for the first time in my life I lived outside of a licensed facility and without older people as my housemates.

My entire life I had lived with various people who, because of being “different,” were considered outcasts by many in society. To the contrary, these folks were *my* mentors, confidants, housemates, and best friends.



*Photograph of the Original Poorhouse in Randolph County (Randolph Public Library)*

**Figure 1. *The Randolph County Poorhouse of the 1800s***

County Homes as of July 1957

<u>County</u>	<u>Superintendent</u>	<u>Location</u>
Alamance	Geo. W. King	Graham
Beaufort	Mrs. Harvey Burgess	Washington
Buncombe	Geo. W. Laster	Asheville, Rt. 4, Box 470
Cleveland	John A. Blanton	Shelby, Rt. 3
Craven	C. N. McDaniel	New Bern
Davidson	A. A. Yontz	Lexington, Box 389
Durham	S. A. Holt, Jr.	Durham, 3711 Roxboro Rd.
Forsyth	Miss Ruby C. Robinson	Winston-Salem, Rt. 7
Gaston	Fred Biggerstaff	Dallas, Rt. 1
Granville	L. B. Newton	Oxford, Rt. 2
Guilford	Mrs. F. B. Gresson <i>R.O. Miles</i>	Greensboro
Halifax	I. P. Bryant	Halifax
<del>Henderson</del>	<del>A. P. Middleton</del>	<del>Hendersonville, Rt. 5</del>
Iredell	John L. Sherrill	Troutman, Rt. 1
Lee	S. H. Campbell	Sanford, Rt. 2
Martin	Mrs. Odessa Barncastle	Williamston
Mecklenburg	John Miller	Charlotte, Rt. 10, Box 242
New Hanover	Herbert Rivenbark	Wilmington
Northampton	W. L. Braswell	Jackson
Person	Ralph W. Eastwood	Roxboro, Rt. 1
Pitt	D. C. Wilson	Greenville, Rt. 2
Randolph	<del>A. L. Williams</del> <i>Vernon Burrow</i>	Asheboro, 1730 Fayetteville St.
Rowan	Percy Smith	Salisbury, Rt. 4, Box 700
Rutherford	Aden Epley	Rutherfordton, Rt. 2
<del>Surry</del>	<del>K. C. Bates</del>	<del>Gebson</del>
Union	John B. Helms	Monroe
Vance	Miss Lucy Taylor	Henderson
Wake	J. A. Holmes	Raleigh
Wayne	Mrs. T. R. Stith	Goldsboro, Rt. 5, Box 17

List of County Home Superintendents in 1957—Our father's name (Vernon Burrow) had been handwritten, as the previous superintendent in Randolph County had recently resigned (NC State Archives)

**Figure 2. The Superintendent List from State Archives**





*Annual picnic of county home inmates, circa 1945. (Personal Family Photograph)*

**Figure 3. Annual Picnic—1940s**



*Annual picnic of county home inmates approximately 1955—Prior to our arrival at the county home.  
(Personal Family Photograph)*

**Figure 4. Annual Picnic—1950s**



*Annual picnic of county home inmates with my family-1960—Facility was still a county home. (Personal Family Photograph)*

**Figure 5. Annual Picnic—After We Arrived at the County Home**





*Annual picnic of rest home residents with my family-1962—Facility had been converted into a rest home.  
(Personal Family Photograph)*

**Figure 6. Annual Picnic—Soon after Rest Home Established**



*Mama, Daddy, David, and John within one month of arriving at the county home. Photo was taken in the front yard of the home. (Personal Family Photograph)*

**Figure 7. Family Photograph from after We Arrived at the County Home**



*My brother John riding a pony at the rest home. The man who is leading him was a resident of the home.  
(Personal Family Photograph)*

**Figure 8. John Riding a Pony in the Front Yard of the County Home**





*Picture of me on the front porch of the family care home where I spent most of my youth. (Personal Family Photograph)*

**Figure 9. Kenny on the Front Porch of the Family Care Home**

## CHAPTER IV

### BETSY

From my earliest memories, Betsy was a part of our family. She came to live with us in October 1970 when she was 60 years old. Although I didn't know it at the time, she had lived in a state institution for the previous several decades. A beautiful lady even in her older years, she must have been quite striking as a young woman. Perfectly milky, unblemished skin complimented her white and gray locks of thick, wavy hair. She stood approximately five feet and four inches, and was somewhat overweight, although she "carried it well."

Betsy's normal speaking voice was literally a whisper. One would have to listen closely to hear her response to a question, the emphasis being on the word *response*, as initiating a conversation was a rare occurrence for her. When she did speak her responses were no lengthier than single sentences, most often being single words. Betsy would sit hours on end staring into space, seemingly living in a world all her own. When she did move, her movement was driven by commands such as: "It's time to eat," "Go get in the car," or "It's time to go to bed."

Betsy and I had a unique relationship. She seemed to think of herself as my caretaker, and likewise (while I didn't realize it at the time), at six years old, I thought of myself as hers. Betsy and I would sit in the living room for hours watching television or



playing games. Actually, I was the one who watched television. Betsy mostly watched me; not in an uncomfortable way, more like a mother would look at her newborn child.

I can never remember Betsy having said anyone's name other than her own and mine. If I pointed to a person (her roommate of many years, or my mother, for example) and asked her, "Betsy, who is that?," a typical response was, "That's Josie Smith," or "That's old Miss Jones," names she seemingly plucked from yesteryear. But if someone else pointed to me and asked, "Betsy, who is that little boy?" Betsy would smile broadly, as if she were introducing her own son, and gingerly state, "That's Kenneth."

A few years after Betsy came to live with us, one of the other ladies who lived in the family care home, Sally, had visitors. Sally's sister, brother-in-law and nephew came to see her. Since we lived in a regular house, there were no specific guidelines that visitors had to abide by. There were no rules, no guest register, and no receptionist to check you in. People simply came to visit just like they would anyone else in the neighborhood. The relatives who came to visit Sally had been there before so I was familiar with them, but I didn't know them well. Sally's nephew was probably 15 or 16 years old, too old to want to play with a kid like me. I was ten years old by this time and found that I was starting to feel more responsible for the wellbeing of Betsy and the other ladies. During the visit, I was in the living room watching television, and my sidekick, Betsy, was not nearby as was typically the case. "Supervisor" that I was, I started looking for her. I went to the kitchen/dining room but Betsy wasn't there. I walked outside to the porch - still no Betsy. Finally, I went to Betsy's room to see if she was in there. The door was closed, which was unusual. I didn't bother to knock on the door. Being a family, we

all just walked into each others' rooms when we wanted. As I opened the door, I immediately realized that I was seeing something that was not meant for me to see. Sally's nephew, one of the visitors, had cornered Betsy against a wall and appeared to be kissing her on the mouth. Both of them were fully clothed. I knew this was not an "okay" situation; yet I simply closed the door. Sally's nephew came out of the room within a few seconds so I knew whatever he had started, had ended when I went in the room. He walked straight to me and said, "You didn't see anything. She just fell against the wall and I was trying to help her get her balance."

For a long time afterwards, I felt guilty for not doing more to help Betsy. Why didn't I rush in there (all 60 pounds of me) and defend Betsy's honor? Why didn't I call for help from my parents who were in another area of the house? Why didn't I go tell his parents? Several years later I figured out the answer to all of these questions, and it was quite simple. I didn't do any of those things because I was only a child and I did what children do when they face scary situations, I retreated. After the visitors left that day, I went to Betsy to see if she was okay. Nothing about her appearance or mannerisms suggested she was ill at ease. I didn't know what to say to her to determine if anything more than what I had witnessed had occurred. I believe I was more upset about the event than she was. That night we watched *The Brady Bunch* together, or rather, I watched the *The Brady Bunch* while she watched me.

Over the next several years, Betsy continued to live with our family, both of us thinking we were taking care of the other. As the years passed, Betsy's health began to decline, and she moved to Randolph Rest Home, and then to Brookstone Haven as she

became more feeble. Sometimes she had to be fed. Her ability to communicate became even more curtailed. Eventually, when asked, she could not tell anyone her own name, but she could always look at me with those sweet eyes and say, “That’s Kenneth.”

The last time I remember seeing Betsy, she had been placed in a secure unit at Brookstone Haven, a setting where she could be safe from wandering. It was the early 1990s, and the state of North Carolina had not become as sophisticated with its standards regarding the type of equipment that had to be used to secure individuals in specific areas. The unit itself was self-contained; however, it was not located in a separate part of the building. While the people who lived in the unit had everything they needed (dining area, living room, bedrooms, bathrooms, etc.), the only object that separated them from the other residents in the facility was a half wall/door/gate. On that particular day, I was in a hurry to do 101 things, most of which were related to completing documentation and filling out forms, tasks that were required by the state, but had nothing to do with providing true care for the people who lived there. As I rushed down the hall, I saw Betsy standing at the gate. I waved at her and started to head to the office, but something stopped me. I turned around and walked back to Betsy, standing there behind that gate. Her hands were on the top of the gate, one on top of the other, laid in a pose suggestive of a hand model. I placed my hands on top of hers and we both stood there looking into each others’ eyes. We spoke no words for several seconds, yet we communicated as much as anyone can communicate with another person. After several seconds I asked her, “Do you know my name?” She hesitated for no more than two or three seconds, and with a voice that sounded softer and weaker than ever, she simply stated, “You’re Kenneth.”

She smiled at me as I let go of her hands and went back to the office to complete my tasks. That was the last time I saw Betsy. She died shortly thereafter. I like to think that Betsy was standing at that exact spot for a reason that day, so we could say goodbye. I still think of Betsy quite often. Any time I am around someone who whispers, I think of her. When I see an older lady with thick beautiful gray hair, she comes to my mind. And when I think of my childhood friends, I think of Betsy.

A few years ago our agency's non-profit entity, *The Cap and Mabel Burrow Foundation*, was having its annual auction fundraiser. Betsy's daughter was there that night. I had seen her a few times through the years, so I recognized her and we spoke for a few minutes. During our conversation the topic turned to Betsy (which is how she referred to her mother, never having been around her very much during her childhood due to Betsy being institutionalized), and how much I had loved Betsy living with us while I was growing up. In response to something I asked, Betsy's daughter replied, "They tell me that Betsy was never the same after the lobotomy. Her whole personality changed." She continued to talk, but I couldn't begin to tell you what words were coming out of her mouth. When she said the word "lobotomy" my mind packed up and left town. I went on a high-speed journey back in time over the past thirty-five years, numerous thoughts racing through my head simultaneously while I attempted to continue to seem interested in another topic that she was discussing. *No wonder Betsy spoke so softly, someone had cut a piece of her brain out. My God, she couldn't remember names because she had been mutilated! What was she like before the lobotomy? Did she talk more? What was her personality like? Was she outgoing, shy, friendly, mean-spirited,*

*happy-go-lucky, reclusive? Why did they do that to her? What warranted such a thing? When did it happen? Would I have known a very different person had Betsy never had a lobotomy?*

The search for the answers to all of these instantaneously acquired questions would be the beginning of my trek to learn more about who Betsy was, and in the process, who I was and am.

### **Betsy's Clinical History**

Betsy Johnson was born in Randolph County, North Carolina in 1910, and was the eldest of three siblings. She grew up in the Randolph County area, and attended school through the eighth grade. After leaving school, Betsy worked briefly in a silk mill. In the mid 1930s, she met and after a brief courtship married Sam Johnson. She gave birth to a baby girl, Minnie, the following year. Shortly thereafter, in April 1937, Betsy became psychiatrically unstable. Her husband, Sam, appeared before the Clerk of Superior Court in Randolph County and testified that Betsy was dangerous to herself and others. An *Inquisition of Lunacy* was completed, and Betsy was sent to The State Hospital at Morganton (currently known as Broughton Hospital). Upon admission to the hospital, Betsy was apathetic to her circumstances and had little interaction with staff members or other patients. When she was examined by the hospital physicians, she admitted to having olfactory hallucinations, indicating that someone had placed poison gas around her house. She felt this was done because she was trying to protect her child. Betsy was also experiencing delusions and entertained a “paranoid trend of ideas.” She

indicated that someone had been trying to dope her, that her husband was in fact her brother, and that someone had been trying to harm her baby.

Betsy remained at the hospital for two years and four months before being probated in August 1939. When she returned home to live with her family, she did well for approximately one month, at which time she started running away from home and walking the highway. In December 1939 she was returned to the hospital when her probation was revoked. Betsy became pregnant during the period of time that she was at home (out of the hospital), and gave birth to a baby girl in August 1940. For the next 13 months, the baby remained with Betsy in the state psychiatric hospital where the hospital staff cared for them. In September 1941, Betsy's mother traveled to Morganton and picked up Baby Joanne to bring her home to Randolph County; however, Betsy remained in the hospital. In 1944 she underwent a sterilization procedure.

There are very few records of what occurred over the next several years; however, a Ward Note dated November 26, 1947 indicates:

Patient eats and sleeps well. She works in the dining room, but will not converse. She is clean and neat about her personal appearance. She walks about as if in a daze, lacks interest and wanders aimlessly about the ward when not at work. Once in a great while she attacks others and it is necessary to put her in seclusion. Weight 187 lbs.

Betsy remained at The State Hospital at Morganton until 1948, at which time she was transferred to Camp Butner (currently known as John Umstead Hospital, located in Butner, North Carolina), another state psychiatric hospital that provided care for citizens with mental illness. Soon after arriving at Camp Butner, hospital staff began

administering electric shock treatments, now known as electroconvulsive therapy. She received a total of 49 treatments. Soon thereafter, hospital officials started communicating with Betsy's mother and asked for permission to perform a lobotomy. With assurances from the hospital staff that a lobotomy was the best treatment for Betsy, her mother consented, and Betsy was lobotomized in 1949. Clinical Notes from July 1952 indicated how the lobotomy had affected Betsy:

STREAM OF MENTAL ACTIVITY

This patient seems to have some difficulty in understanding. Most questions have to be repeated several times before she answers in a very soft voice.

ORIENTATION

Day? "Saturday," (Tuesday). Date? "June 5, 1919." Place? "California." Who are you? "Jessie Smith." Who am I? "Joe."

MOOD

How do you feel? "All right." Are you happy? "Yes." Ever feel sad? "No."

CONTENT OF THOUGHT

Delusions and hallucinations are denied and cannot be elicited. Denies suicidal or homicidal tendencies.

MEMORY

Remote, recent and immediate memory are poor. She does not know her age, does not remember that she is married or has a child.

In 1961, Betsy had a total hysterectomy. She remained at Camp Butner until August 1965 where she was visited regularly by her mother and daughters. At that time she was transferred to Dorothea Dix Hospital in Raleigh, North Carolina. While residing at Dorothea Dix, Betsy stayed on an open ward and reluctantly participated in activities. She was very quiet and stayed in bed most days. The hospital staff encouraged Betsy to

participate in Industrial Therapy assignments and by the time she was released from the hospital in 1970, she was working regularly in the kitchen and appeared to be more outgoing.

Upon discharge from the hospital in October 1970, Betsy was placed at Burrow's Rest Home in Asheboro, North Carolina. Her discharge diagnosis was Chronic Schizophrenia. The medications that she was taking were Navane 10 mg twice daily and Kemadrin 5 mg twice daily. She was monitored by Randolph County Mental Health Center for psychiatric follow-up. A Clinical Note from 1972 mentions Betsy becoming upset by the crying of a newborn baby who was brought by a visitor into the home. Betsy was unable to express why the baby's presence upset her. A psychiatric note from 1973 indicates that Betsy was experiencing an increase in leg movement to the point that her entire body would begin to shake. Her medication was decreased in an effort to control the movements. Another psychiatric note from March 1976 states:

She was smiling broadly and, seemingly, in a good mood. She was only partially oriented. She knew that today was Thursday, but guessed that the month might be June and the date the 5<sup>th</sup>. She estimates that she has been at Burrow's Rest Home about 6 months, when in reality she has been there 6 years; therefore, I think we could safely say that her memory is grossly impaired, and so is her judgment, and she has little, if no, insight into the nature of her problem. She does deny, rather adamantly, the presence of delusions or hallucinatory experiences.

Betsy remained at Burrow's Family Care Home, where she assisted with household duties when instructed, until the late 1970s when she moved to Randolph Rest Home. After moving into the rest home, Betsy had few visitors. Her mother had died, and her daughters, who had never really known their mother and referred to her as "Betsy,"



found it too disturbing to see her. Her youngest daughter found the visits so disturbing that afterwards she would return to her own home and retreat to her bedroom for several days.

Throughout the 1980s, Betsy continued to be followed psychiatrically by Randolph County Mental Health Center. By 1982 Betsy's psychiatrist had added a diagnosis of dementia. A February 1982 psychiatric note states:

Betsy comes in today as organic as ever. She hardly knows her name. The administrator says that she is doing as well as she usually does which includes having to be told to go to the table to eat, to lift up her fork to eat. She has to have clothes taken out for her and sometimes she will dress herself. She is incontinent at times of both urine and feces in the living areas. It seems now that her senility dominates the clinical picture as contrasted with her schizophrenia and it is not clear whether a major tranquilizer is needed for her senility.

Physicians' notes from that period of time consistently mention her poor memory, and several notes pointed out that she did not always know her own name; however one note from February 1988 states:

Betsy comes in as organic as ever. She did recognize Kenny today which is quite remarkable since often times she isn't able to say her own name.

In 1989, at the age of 77, Betsy experienced a psychotic episode which resulted in a brief psychiatric hospitalization. According to the psychiatrist's notes she believed she was a "burlesque queen," was removing all of her clothing in the common area of the rest home, and was attempting to elope. She also admitted to experiencing auditory hallucinations and appeared to be responding to the hallucinations as the psychiatrist was

interviewing her. Betsy returned to the rest home one week later, and was no longer exhibiting delusional behavior.

In November 1990, Betsy moved to Brookstone Haven of Randleman when Randolph Rest Home closed. Due to her increased confusion and a propensity to wander, she was placed in a secure Alzheimer's Unit. For the next few years Betsy continued to regress, requiring more assistance with her activities of daily living (ADLs). In August 1993, at the age of 83, Betsy developed pneumonia and was admitted for treatment at the local hospital. Her illness grew worse and on August 22, 1993, at the age of 83, Betsy expired while still in the hospital (Mental Health Records).



*This is the only picture I could find of Betsy. She is the gray-haired lady in the middle of the photograph. The little boy behind her is me. (Personal Family Photograph)*

**Figure 10. Betsy**

## **CHAPTER V**

### **SALLY**

Sally Jackson came to live with us in the family care home when I was eight years old. She was thin in stature, weighing no more than 110 pounds, and stood approximately five feet and four inches tall. Sally was legally blind and wore very thick glasses, but she could see to get about in familiar settings. Before Sally moved in, Mama told me that she had a bit of a temper, but I don't think that was quite accurate. Not that Mama was being untruthful, but the reality was, Sally had a hell of a temper as we all found out soon after she moved in with us.

Sally scared a lot of people, but I found her very fascinating. Although I didn't know it at the time, she probably had some type of explosive disorder. If things didn't go her way, she would pitch one heck of a fit. As a child, I never finessed the art of reading Sally, so I never knew when things weren't going her way. I would be walking through the house minding my own business, and out of nowhere, I would hear a scream that would make you jump out of your skin. I would run to the area from whence the scream came (I couldn't avoid the spectacle of it all), and there would be Sally, arms flailing and legs kicking. The objects of her attacks were typically Mama or Daddy. She never attacked me. Of course, I never gave her an answer that she didn't want to hear, namely, "No."

Most of Sally's temper tantrums were related to food. She was a very finicky eater, and she would let you know in a heartbeat if the meal that was set before her was one that she liked, or if it would end up in your face. I vividly recall one day when Sally was upset with the meal that Mama had prepared. As I entered the kitchen, which also served as the dining area, Sally, who was sitting at the table, screamed and threw her plate, food and all, across the room. Her plate looked like a Frisbee with corn and beans flying everywhere. I ducked back into the hallway as Sally jumped to her feet and lunged at Mama. You would have thought that Mama had just asked Sally if she wanted to step into a boxing ring, or had called her a horrible name, but neither was the case. Before Sally could reach Mama, Daddy stepped between them and started blocking kicks and punches as best he could, all the while backing Sally into her room. Even though there were no therapeutic holds in that day (physical interventions to protect an individual from hurting himself or others), Daddy was always careful not to harm Sally. This was not the first time that Sally had attempted to attack someone (and succeeded many times), nor was it the last. I stayed out of the way, but I could not help but watch the action. Once Sally was in her room, she screamed and hit herself for 10 or 15 minutes, then deescalated down to a passive state, acting as if nothing had happened. She was smiling and laughing shortly thereafter.

A few months later, I was outside playing with my BB gun. Sally walked out to the porch and was looking out at the yard. Because of her poor eyesight she couldn't go very far into the yard because she could not see where she was stepping. I suppose mischievousness got the best of me. Not meaning to actually hit her, I shot a BB at the

chimney. The BB hit the chimney, then ricocheted toward the porch and hit Sally in the arm. She immediately yelled and started crying. I ran to Sally, not certain if she would pummel me when I arrived, but positive that Mama would if she saw what I had done. My primary goal was to stop her from crying. Luckily, once Sally realized that she wasn't hurt, I was able to calm her to the point that she started laughing. That remained our secret. I suppose I have to give Sally credit. She was no snitch. I never did tell Mama either.

Sally's family members were quite understanding of how challenging her behavior could be. One of her sisters, Billie, once told us, "When Sally was ugly and got to fightin', Mama would put the couch on her head and then we'd all sit on it." To this day I can't exactly reckon what that meant. As a child I envisioned it like this: Sally's family casually sits on the sofa carrying on a conversation and drinking iced tea while Sally is sprawled out on the floor, her head trapped by the sofa, and her arms and legs rotating like helicopter blades.

After one too many attacks, Sally had to be hospitalized again, and later moved into Randolph Rest Home. Mama and Daddy had blocked punches as long as they could manage to do so. They were both getting older, and fighting wasn't in their blood to begin with, so another setting became necessary. At the rest home, there were more staff members, which made it easier to keep things under control if Sally became agitated. I still saw Sally when I visited the rest home. We would talk about her radio, which she loved to play, and visits from her family, or she would show me her writings. These

writings were page upon page where she had practiced printing her name. I always bragged on her for doing such a good job.

Years later, when I moved to the rest home to start working there, Sally was still a resident. One would think that age would have slowed her down, but to the contrary, she continued to be very confrontational when she felt that someone had wronged her. As I had grown up, I had learned to read Sally's moods. I realized that the best way to maintain a calm atmosphere when she started showing signs of anger or agitation was to joke with her. If you could keep her mind off of the issue that was upsetting her, she would typically calm down. Unfortunately, there were still those occasions when no amount of joking or calm talking could deescalate the situation. In addition to the issues with anger outbursts, Sally had epilepsy. Her medication levels had to be watched very closely to ensure her seizures didn't get out of control.

In 1987 Sally had to be committed to a psychiatric hospital when her behavior became too aggressive for us to manage. When she was discharged from the hospital, she moved to another rest home in her home county of Alamance. From there, I lost track of her. It wasn't until I started this study, and read her mental health history, that I knew what happened to Sally after leaving Randolph Rest Home.

### **Sally's Clinical History**

Sally Jackson was born in July 1928 in Alamance County, North Carolina. At six months of age, Sally began having seizures and displayed signs of slow development. Around that same time, doctors determined that Sally was totally blind in her right eye and partially blind in her left eye. Over the next several years, her mother, Mrs. Dorothy

Jackson, attempted to meet Sally's needs at home, which was quite challenging since Sally started having "temper tantrums" at a very early age. When Sally was eight years old, Mrs. Jackson gave birth to another daughter, Sue. Soon thereafter her husband died and within two years, Mrs. Jackson had remarried a man named Robert Lemmonds. Unlike Sally's biological father, Mr. Lemmonds was not sympathetic to Sally's situation. He immediately began to place pressure on Sally's mother to have Sally institutionalized. At the age of ten, Sally was sent to Caswell Training School, a setting in Kinston, North Carolina that was originally opened in 1911 to provide services for the "feebleminded." (<http://www.caswellcenter.org/index.aspx>) At the time of her admission, testing revealed that Sally had syphilis, which she had apparently had since birth, as social workers discovered that both parents also had syphilis. Sally remained at Caswell Training School until 1945 when, at the age of 17, she returned home to live with her mother, sister, step-father, and a new step-sister who had been born while Sally was in the institution.

For the next 22 years, Sally continued to have intermittent explosive behavior, at times having physical fights with various family members who stood between Sally and what she wanted. Sally's mother attempted to be the peacekeeper, always giving in to her demands in order to prevent an outburst. By 1967, Sally's step-father had passed away and both sisters had married and moved away. Sally continued to live with her mother, who was in her 60s and unable to take the physical abuse that Sally continued to display. In June of that year, Sally's mother had her committed to Dorothea Dix Hospital in Raleigh, North Carolina. Sally was there less than a month before the doctors were ready to discharge her. Feeling that she had no other alternative, Sally's mother agreed to let

her return to the family home, as long as the doctors would ensure that she was “tranquilized.” At the time of her discharge from the hospital, Sally’s diagnoses were Mental Deficiency, moderate with Behavioral Reaction and Convulsive Disorder. The following year, Sally was taken to Randolph County Mental Health Center where she was followed by a psychiatrist. A Clinical Note from September 1968 states:

This young lady is obviously mentally defective. As with most mental defectives the problem becomes one of behavioral disturbance as they get older. Apparently Miss Jackson has temper tantrums from time to time, but compared with most people who have the similar amount of pathology, she seems to be getting along exceedingly well. Her mother came with her and she reported that she does religiously take her medicine and that, in general, she is not difficult to get along with.

Over the next five years, Sally’s mother continued to provide care for her in the family home, but stopped receiving services through the mental health center in 1970. In August 1973, Sally’s mother died unexpectedly leaving Sally without a caretaker. The following is a clinical note from a mental health nurse dated August 15, 1973:

Sally Jackson has not been seen at the clinic since 1970. Mrs. Luther, her social worker, called stating that Sally’s mother died recently and that Sally was totally dependent on her. Sally has two sisters, but both seem somewhat afraid of Sally and are unable to accept her in their home. Consequently, Sally was placed at Sylvia’s Rest Home but has been having an adjustment reaction since then and has hit other residents in the home, has been cursing and lashing out at people nearest to her. Sylvia has called Mrs. Luther quite upset about the situation and does not know how long she can tolerate Sally and also with Sylvia feeling that both Mrs. Luther and myself needed to give her a great deal of support and encouragement in helping Sally Lee work through this adjustment reaction. I later talked with Sylvia and she seemed to be handling the situation fairly well. She reported that Sally had calmed down by the next day and was sleeping very well. She is prepared to give Sally a period of time to work through this and it was Sally’s mother who had encouraged her to take Sally should anything happen to



her. Hopefully by working closely with Sylvia on a consultation basis hospitalization can be prevented here.

Apparently the cease in inappropriate behaviors did not last very long, and the attempt to prevent hospitalization did not work, as on the following day, at the age of 45, Sally was committed for the second time to Dorothea Dix Hospital. The summary of her hospitalization describes her as being friendly and cooperative. She talked freely about her mother's death, which would lead to periodic bouts of crying. She remained in the hospital for one month and was discharged to Burrow's Family Care Home. Her discharge medications were Dilantin 0.1 gm with Phenobarbital grains  $\frac{1}{4}$  three times daily and Thorazine 100 mg twice daily.

By November 1973, two months after her admission to Burrow's Family Care Home, Sally had started displaying disruptive behavior. A note that was written by her mental health nurse states:

Mrs. Burrow called indicating an incident that occurred this morning. Apparently Sally became quite rebellious, as she has in the past, when she has to conform to rules and regulations. Mrs. Burrow is quite concerned over Sally, however, she is willing to try to maintain her in the home. She states that she feels Sally is rotten, spoiled greatly and resents any form of authority. However, if this incident occurs again she plans to contact this therapist, and an appointment will be set up with the psychiatrist to discuss the medication regime to see whether or not increasing her medication might help these temper outbursts.

Sally continued to have intermittent outbursts, and on May 6, 1974, she required another hospitalization at Dorothea Dix Hospital. Although the admission assessment indicated that the hospitalization should last no more than one month, Sally remained in the hospital for nearly two years. During her stay at Dorothea Dix, Sally had cataracts

removed from both eyes, though she remained legally blind. She also required surgery on her left ankle after sustaining a fracture due to being “pushed down on the bathroom floor on her ward.” There was no indication in the medical record as to who pushed her down. A long leg cast was applied after the surgery, and she was returned to her home ward at the hospital where she received physical therapy to improve her gait.

On March 24, 1976, Sally was discharged to Randolph Rest Home. Her discharge diagnoses were Mental Retardation, moderate, and Epilepsy, and her discharge medications were Thorazine 100 mg twice daily, Dilantin with Phenobarbital ¼ capsule in the morning and two at bedtime. Within days of being admitted to the rest home, Sally was enrolled in a day treatment program at Randolph County Mental Health, although she attended only one day per week.

Over the next few years Sally continued to live at Randolph Rest Home, having occasional behavioral outbursts that were manageable by the rest home staff. By the late 1970s her seizure disorder had worsened, and she was having frequent blacking out episodes. In July 1980 Sally experienced a series of strokes that required a hospitalization. Afterwards, she was discharged to a nursing home in Lee County where she could receive skilled nursing care. She remained in the nursing home for one month then was transferred to a rest home in the same county. In March 1981 Sally returned to live at Randolph Rest Home so she could be closer to her family members. She remained at the rest home until June 1984, at which time she fell and fractured her hip. She was once again placed in a skilled nursing facility, this time in Chatham County. She remained there for six months and was transferred back to Randolph County. Since there

were no vacancies at Randolph Rest Home, she was placed at another rest/retirement home in the area. The home where she was placed was unaccustomed to providing care for people with behavior disorders, and within one week of admission, she was discharged for attacking her roommate. By this time a vacancy had opened at Randolph Rest home, so she moved back into that setting. In June 1987, though legally blind and using a walker to ambulate, Sally attacked another resident and was committed yet again to Dorothea Dix Hospital. She remained in the hospital for three months and was discharged to a facility in Alamance County. Within days of being admitted, Sally started a fight with another resident and was severely beaten by that individual. She was returned to Dorothea Dix, and in July 1987 she was discharged to a rest home in the eastern part of North Carolina, several hours from her family members.

For the next 10 years, Sally had no contact with Randolph County Mental Health Center. On April 15, 1997 a case manager with Randolph County Mental Health contacted Sally's sister, Billie, who informed the case manager that Sally was living in a nursing home in Elizabethtown, North Carolina. The following day the case manager travelled to Elizabethtown to visit Sally. The following is the case manager's note from that visit:

Visit to see Sally Jackson at nursing center. Sally is hard of hearing, wears glasses and uses a wheelchair to get around in. She is total care for her ADLs but can feed herself and propels her wheelchair. She is active in activities in the nursing center, eats meals in her room. Explained who I was and what reason I came to see her. She was agreeable to having me be her case manager and coming to see her. Her chart was opened. Sally said she would like to see her sister Billie.

Over the next several months, the case manager had frequent contact with Sally's sister regarding guardianship issues, and the possibility of Sally moving closer to Asheboro where she could be near family members and church friends. Each month, the case manager would visit with Sally in the nursing center to ensure she was receiving appropriate care. On each visit Sally mentioned wanting to see her sisters. Each time the case manager documented a conversation with Billie, she (Billie) inquired about Sally being moved closer to Asheboro. Billie explained to the case manager that it was difficult for her to travel long distances, as her own health was poor; therefore, she could not drive to see Sally.

In September 1998 Sally had the remainder of her teeth pulled and was placed on a "soft diet." When visited by her case manager in February 1999, Sally indicated that she would like to have false teeth because she was unable to chew food.

In August 1999, the nursing home staff reported to the case manager that Sally had attacked another patient in the facility because she thought the other patient had been in her room and taken some items. The nursing staff also reported that the opposite was the case, that Sally had been in the other patient's room. It was also noted that Sally's psychotropic medication had recently been reduced.

On November 27, 1999, nursing notes from the facility indicated that Sally had been experiencing difficulty eating. At one meal she was coughing and vomiting after lunch and was taken to the local emergency room for evaluation. Another note on December 3, 1999 stated that Sally was having difficulty finding her food on her plate due to poor eyesight, and that she was taking "big bites without chewing."

On December 13, 1999, a case management notes states:

Contacted by Sally's nephew and informed that Sally died yesterday. Contacted the nursing home and spoke with the social worker who reported Sally was eating supper and started choking on some meat and 911 was called and the EMTs suctioned Sally. During the process they logged food further down her throat. Apparently, at that point they transported Sally to the hospital and at the hospital an incision was made in her throat and a tube inserted and she was placed on a ventilator. Sally never recovered and expired that same day.

Sally never returned to Asheboro prior to her death, nor did she see her sisters as she had mentioned wanting to do during each case management visit (Mental Health Records).



*Sally at one of the annual picnics in the mid 1970s. (Personal Family Photograph)*

**Figure 11. Sally**

## CHAPTER VI

### SIMON

I suppose Simon Perkins was the first gay man I ever met. At least he was the first openly gay man I ever met. Of course, I didn't know that Simon was gay because I didn't know what gay meant. The only term that I had ever heard to describe someone like Simon was queer. I did realize that Simon was "different" from most of the men I knew. Simon was effeminate with his gait, his speaking voice and his mannerisms. He came to live with us in the family care home when he left Jewel's Family Care Home, another facility that was located in Randolph County. I was about seven years old when he moved in with us. I never knew why he left Jewel's, but from what I had heard about her, Jewel wasn't one to put up with foolishness, and some folks considered Simon quite foolish. I didn't mind him though. I liked Simon's sense of humor. Even as a child he made me laugh, and the laughing was truly laughing with him, not at him.

A rather short man with a oversized mid-section, Simon weighed about 180 pounds, had solid white hair that was very thick and always wore bib overalls. He also dipped snuff. Most of the time when you saw him he had a small bulge just below his lower lip. He was very neat with his tobacco habit. I don't remember seeing him untidy with his snuff until years later when he had become quite frail. When he walked, in addition to being feminine with his gait, he leaned slightly to the left. He also had trouble raising

his left arm. I never asked him why he couldn't lift it more easily. It just didn't dawn on me to inquire.

Even though he stayed with us in the family care home longer than he stayed at Jewel's, it wasn't more than several months. While I thought he was fun to be around, apparently Mama wasn't as enamored with his sense of humor. In retrospect, I wonder if Mama and Daddy were concerned about Simon's sexual orientation, and the possibility that he would "bother" me or "rub off" on me. Regardless of the reason, Simon moved to Randolph Rest Home, the old county home, in the early 1970s. After he moved, I only saw Simon when I went to visit at the rest home. It wasn't until I was 18 years old, and moved in the apartment above the rest home that I once again saw Simon daily. By this time, Simon had started going downhill physically. He shuffled when he walked, had problems with his blood pressure, and had experienced several small strokes. During the entire time I worked at the rest home, Simon received frequent visits from his older brother, Jacob.

I figured out that Simon was gay one spring afternoon in 1983. The laundry room for the rest home was located in a basement. In order to get to the basement, you had to go outside of the building and walk down a flight of concrete steps. On that particular day, I was responsible for doing the laundry. As I started to go into the door that led to the laundry area, Simon and another gentleman named Bill, who had been a resident at the facility since before our family went there, were coming up the steps. Simon was leading the way, and Bill was right behind him. When he saw me, Bill looked down at his zipper, and immediately zipped up his pants. Simon walked right past me with a big grin

on his face and said, “Everybody needs a little fun now and then.” As naïve as I was, I immediately knew what he meant. I didn’t know what to say, so I just stood there with an armful of laundry and watched as they both walked back into the building. I never said anything to either of the men about the incident since I figured it wasn’t any of my business.

Simon had a ritual that he would perform everyday, sometimes several times throughout the day. Whoever was working in the office would receive a visit from him, and he would state, “I used to be the Worthville hermaphrodite, but they sent me away to the state hospital because no one believed it. If you don’t believe me, just ask the doctors.” One of his other sayings was, “It runs up the pipe and down the leg and through the water fountain.” My typical response was to look up from the work I was doing and say, “OK Simon. Thank you for letting me know.” I never did figure out what was running up the pipe or down the leg, and I didn’t have a clue as to what the water fountain had to do with it. Although Simon was different in the eyes of many people, I never remember anyone at the rest home ridiculing him for his actions or behavior. None of the other residents called him names, and none of the staff members scorned him.

In August of 1985, I went with a group of residents and staff members to the state fair. Simon was among the crowd. When we arrived at the fair, I was assigned to look after him and two other residents. We had a great time that day. We rode rides, ate cotton candy and hot dogs, played games then ate some more. At the end of the day we all got on the church bus that had taken us to Raleigh. When we were about 30 minutes from home, Simon started complaining of indigestion. Someone on the bus had some Roloids



so we gave him one and he seemed to be fine within a few minutes. Within an hour of arriving back at the rest home, Simon was complaining of chest pain. We immediately called an ambulance and transported him to the local hospital. The emergency room physicians conducted some tests and determined that he was in the process of having a heart attack. He was transferred to the cardiac unit where he stabilized. We visited him each day while he was there and the nurses reported that he was doing well. About a week after being admitted to the hospital, Simon had another heart attack and died suddenly. All of the staff members and residents were stunned. Everyone had expected Simon to make a full recovery and to be walking around the rest home making his peculiar comments again.

A graveside service was held for Simon in Worthville, the town he had so frequently referred to when he spoke of being a hermaphrodite. His older brother Jacob was there and wept openly. I cried too. Some of my tears were for the loss of Simon, but more were for the older man I saw before me who was heartbroken over the loss of his baby brother, a man who had spent decades of his life locked away in a state hospital.

### **Simon's Clinical History**

The youngest of several boys in his family, Simon Perkins was born in Randolph County, North Carolina in 1913. As a young boy, while his brothers helped their father with outside work, Simon was drawn to assisting his mother in the kitchen and with other household duties. Simon completed the fifth grade, but went no further in school. When he reached his teenage years, Simon did not follow in his brothers' footsteps by courting and marrying, rather he continued to live at home with his parents. As he reached

adulthood, he started working in a furniture plant close to his home. During this period of time, Simon began making sexual comments about other boys in the neighborhood. Much to his family's dismay, he showed a proclivity of a sexual nature to other males. Even more, he commenced stating that he was a hermaphrodite, specifically, "The Worthville Hermaphrodite." His family members discouraged this type of behavior, but at the same time, they were very protective of him if others in the neighborhood made derogatory remarks.

In his late 20s, Simon was drafted for World War II; however, he was released from duty when his "psychopathic nature was noted." In July 1942, Simon's behavior escalated to the point that his family could no longer tolerate it. In addition to the sexual inappropriateness, he became disheveled and started using offensive language. Feeling he had no other alternative, Simon's father appeared before the Clerk of Superior Court in Randolph County and requested that Simon be committed to a psychiatric hospital. At the age of 31, Simon was taken to the State Hospital in Morganton where he received a diagnosis of Psychosis with Psychopathic Personality. The Clinical Notes at the time of his admission indicated:

The patient revealed delusions about his body and his sexuality. He felt that he was a woman inside in spite of his male organs. He also felt that his mother and father were against him. Before admission he became slovenly, used vulgar talk and said that some "stuff" was running out the top of his head and down his legs.

In September of that same year, Simon was released on probation and returned to Randolph County to live with his parents. There he remained for the next three years, continuing to display behavior that his family found unacceptable, but tolerated as best

they could. According to his medical records, in April 1946, Simon's conduct escalated to the point that his family felt commitment to the state hospital was necessary. Yet again, Simon was taken to Morganton, but this time, he would not see his hometown for many years.

In 1950, Simon was transferred to Camp Butner, another state hospital that had opened within the past few years. On September 19, 1951 he was lobotomized. His records do not indicate why this decision was made, or if anyone in his family granted permission for the procedure. During that same month, Simon sustained a broken arm, but again, it is unclear how this occurred. Simon continued to reside at Camp Butner until 1965, at which time he was transferred to Dorothea Dix Hospital in Raleigh, North Carolina. In 1967, Simon suffered another broken arm. Although there is nothing in the record that specifically indicates how this occurred, a clinical note does imply what may have happened.

The patient is almost always a cooperative one according to the chart. He seems particularly eager to please and to do what is asked of him. Only occasionally has he shown a flash of temper or stubbornness. He is occasionally involved in fights with other male patients, usually on the losing end.

Simon remained at Dorothea Dix Hospital until 1970, at which time he was deinstitutionalized to his home county. When he moved out of the hospital, his discharge medication was Stelazine, 10 mg each morning, Donnatal, 1 tablet twice daily, and Thorazine, 200 mg twice daily. His discharge diagnosis was Chronic Schizophrenia, post lobotomy. The discharge summary from Dorothea Dix Hospital stated,

The patient is very fond of trips and hospital social activities. He also prefers to associate with women. He is not overtly homosexual at this time. After 28 years of hospitalization, it was felt that he could be moved to a boarding home. He seemingly had no hesitation in leaving the hospital and was very enthusiastic about the change upon leaving.

When he left the hospital, Simon moved to Jewel's Family Care Home in Randolph County. He remained there a very short period of time before being transferred to another family care home in the area, Burrow's Family Care Home. Once again, Simon's stay was brief, as he was transferred to Randolph Rest Home within several months, and began receiving psychiatric follow-up from Randolph County Mental Health Center. While living at Randolph Rest Home, Simon was a friendly and outgoing individual. His mannerisms were considered to be feminine; from the way he walked and talked, to the manner in which he daintily held his eating utensils. It was customary for Simon to converse freely with people, often having exchanges that were perfectly relevant. However, it was not uncommon for Simon's conversations to segue into nonsensical comments about "locks and keys" being placed on his body, and he continued to frequently refer to himself as "The Worthville Hermaphrodite." A clinical note that his therapist wrote in 1977 states,

Patient is obese, white-haired man with high-pitched lisping speech. He reports "I was born a hermaphrodite." Sexual delusions still abound.

Another note that was written by his psychiatrist states,

Simon comes in doing well. Same complaints. He talks about the same crazy stuff with few variations. I told him that he needed to learn what thoughts he has are crazy and not talk about those and he continues to talk about them. The people at

the rest home have learned to tell him to keep it to himself and not talk that way to them which I think is a good approach. It is generally best to stay away from this. He states that if his medication was taken away from him he would become crazy which is probably true. He is chronically psychotic.

Although Simon did not have a large number of guests, he was frequently visited by his older brother, Jacob. While he appeared perplexed as to how to respond to Simon's conversations about his sexuality, Jacob was never observed by the rest home staff as being harsh or unkind to Simon. He always spoke to Simon in a calm and reassuring voice, and made it clear to Simon and to the rest home personnel that he cared deeply about Simon and his wellbeing.

Over the next few years, Simon's physical and medical condition began to deteriorate. By the early 1980s, now in his late 60s, he had experienced numerous medical complications. A neurological examination from August 1982 stated the following:

Past medical history reveals that he has had some numbness in his right hand mostly related to his old shoulder injury. A long history of hypertension, a blackout spell lasting approximately ten minutes one evening while in the rest home and his head surgery, bilateral frontal leucotomies (lobotomy). He is having continued problems with gait and is no longer willing to dress himself. He has urinary incontinence and because of this wears a diaper. He also has a tendency to fall and has fallen on many different occasions though not striking his head. The gait examination revealed a decreased right arm swing, he had circumduction of the left leg. With Romberg testing he tended to fall to the left and on gait examination he tended to fall to the left. It was noted that in addition to the above that the right corner of the mouth was decreased versus the left and at times with the Romberg he would also tend to fall to the right. This patient has a frontal lobe syndrome in addition to his chronic undifferentiated schizophrenia. This can aggravate both gait and urinary symptomology. In addition to the above he has most likely had a right brain stroke in the past in view of some subtle findings in the right brain. His general exam was not done but he had prominent breasts and decreased rectal tone. This patient has several different problems. 1) Chronic

undifferentiated schizophrenia 2) Urinary incontinence with decreased rectal tone most likely secondary to medication plus bilateral frontal lobe leucotomies plus right brain stroke. 3) Gait disturbance most likely secondary to brain stroke. I would recommend that we would try and taper off this patient's Artane and increase his Banthine. I doubt that this will be successful since his dysfunction supranuclear basis but think this might be worth a try.

In October 1985, Simon had a heart attack and was transported to Randolph Hospital. He remained there for several days and nursing personnel reported that he was improving; however, on the evening of October 31 he had another heart attack, massive this time, and could not be revived. Simon was survived by his older brother, Jacob (Mental Health Records).



*Simon sitting in the living room at Randolph Rest Home. (Personal Family Photograph)*

**Figure 12. Simon**

## CHAPTER VII

### EMMA

Emma Baldwin moved into Randolph Rest Home in 1980 after residing several decades at Dorothea Dix Hospital. I was in high school at the time, and I visited the home quite regularly to see my sister, Lou, who was operating the facility. The first time I saw Emma she was racing down the halls of the facility. I use the word “racing” because that was the primary way Emma traveled from one end of the building to the other. She would jump up from the couch in one lobby and travel as fast as she could to the other lobby. As she reached her destination, she would practically dive onto the couch, reminiscent of a baseball player diving for home plate. She would lie on the couch for a few minutes, sit up then race to the other side of the building where she would once again successfully “steal a base.”

In the first several months of Emma’s stay at Randolph Rest Home, this ritual would continue throughout the day and into the night, with her stopping only to use the restroom or eat a meal. If Emma did sit still for a few minutes, she would carry out another routine. She would place the tips of the fingers of her right hand to the right side of her forehead then immediately outstretch her arm, slightly elevated above her head, with her fingers still splayed. If you were not accustomed to observing this movement, you would think she was admiring her freshly polished nails; however, she never looked at her hand. She simply repeated this routine until she decided to jump up from the couch and race to the other side of the building. When she elected to go to bed, she would jump

up from the couch and, not one to waste time, start tearing clothing off as she headed to her bedroom. It mattered not who was present to see this display. Emma was an equal opportunity stripper. She stripped in front of the preacher during facility services so many times that he finally stopped complaining about it and ignored her.

By the time I moved back into the rest home after graduating from high school, Emma's institutional behaviors had decreased. Though she was still quite active, her racing days had started to dwindle, and the hand ritual was also waning. As Emma became more familiar with the rest home and her surroundings, she started to bond with staff members. Her favorite person was whoever was in charge of the facility. At that time, it was Lou. Emma would sit in Lou's office as long as Lou would sit there. When Lou got out of her chair to walk down the hall, Emma was right behind her. When Lou went to the post office, Emma practically beat her to the car.

When I became the manager of the facility, I became the new "Lou" in Emma's eyes. Although Emma spoke well, she never could pronounce my name correctly. Instead of "Kenneth Burrow," it came out as "Kennis Burse." I finally gave up with my attempts to correct her; Kennis Burse it was. She would sit with me in the office where she would remain quiet the majority of the time, only interrupting me occasionally to seek attention. There were two forms of attention seeking behavior. One would be a cry that came out of nowhere as Emma would wail, "My hand hurts. My arthritis (pronounced arperidus) is killin' me." Taking her hand in mine, and rubbing it for several seconds was usually the perfect cure for this particular ailment. The second form of attention seeking behavior occurred when one of the other residents had the audacity to walk into the office when



Emma was sitting in her chair (and as far as she was concerned, it was indeed her chair). The unlucky individual who came into the office would typically hear, “Get outta here! You ain’t got no business in here.” No matter how many times I tried to remind Emma that everyone had just as much right in the office as she did, it never stuck. The next time someone came near, that person got the same “friendly” greeting.

Emma hated most men. I often wondered if there had been an incident or incidents when she was in the state hospital that caused her to be so distrusting of men. She claimed that she had a baby while she was in the hospital. No matter how many times she was asked, she always stuck to the exact same story. It went something like, “I had a baby at Dix Hill but they took her away from me. Her name was Linda. I loved that little baby but they wouldn’t let me keep her.” I heard that story so many times that I finally called Dorothea Dix and spoke with a lady in the medical records department. She called me back a few days later and told me there was no record of Emma having a baby while she was at the hospital. I still believed Emma.

Over the years, Emma had a few psychiatric hospitalizations when she would decompensate, but those were few and far between. For the most part, she steadily learned to live outside the walls of an institution and among other members of society. In 1990 when Randolph Rest Home closed, Emma moved to Brookstone Haven with the other residents who left the old county home behind. The first few years at Brookstone Haven were uneventful for Emma. She continued to stay in the office as an “assistant” for whoever was in charge. Her racing the halls remained at a minimum and the hand movement had completely disappeared.

In 1992, Emma started displaying disruptive behaviors. She would start arguments with the other residents, cry incessantly, and fall to the floor for no apparent reason. After several months of this disruptive behavior, Emma was once again hospitalized. Upon discharge from the hospital a case manager from Randolph County Mental Health Center was assigned to her, and it was determined that Emma would do better in a smaller setting. Our agency operated two group homes for older people with developmental disabilities, and Emma moved from Brookstone Haven into one of the group homes. Emma started receiving true habilitation, and for the first time since she had been deinstitutionalized, limits were set regarding inappropriate behavior.

At first Emma was resistant to any type of training, but she slowly started to respond. Just like everyone else who had provided care for Emma at Randolph Rest Home and Brookstone Haven, the staff at the group home fell in love with Emma. Although she had been fairly active in the two previous settings, Emma had opportunities to participate in activities like never before in a small setting where the staffing ratio was greater. She went out to eat, to the movies and the library, attended festivals and carnivals, and went on annual vacations. In 1996, Emma traveled to Disney World, on an airplane no less. Emma couldn't quite grasp the concept of air travel. The entire time the plane was in the air, she thought she was on a bus, and told the staff members they were liars when they tried to convince her otherwise.

In 1998 Emma's health started to decline. She was admitted to the local hospital on several occasions for various ailments, with her primary issue became her inability to swallow food without aspirating. After one of her hospitalizations, she was placed at a

local nursing home for rehabilitation, and returned to the group home approximately four weeks later. Shortly thereafter, she required another hospitalization due to pneumonia.

We hoped that she would improve and be able to return to the group home; however, that was not meant to be. On July 21, 1998, Emma died. Her death certificate listed aspiration pneumonia as the cause of death.

### **Emma's Clinical History**

Emma Baldwin was born in May 1916 in Seagrove, North Carolina, one of 10 siblings. Emma's father was a farmer and her mother a homemaker. From an early age, Emma's parents realized that she needed extra attention. By the time she was 10 years old, she was having "fits" that the family did not know how to handle. She would fall to the ground with her body shaking uncontrollably for several minutes. After each episode, she was lethargic and unaware of what had occurred. Over the next few years, the fits intensified and were more frequent. Feeling they could no longer manage Emma in the home, her parents appeared before the Clerk of Superior Court on February 18, 1932 and requested that Emma be institutionalized. The document that was completed, an

*Inquisition of Lunacy* stated the following:

Emma Baldwin, An Alleged Lunatic. BE IT REMEMBERED, That on the 18 of February, 1932, personally appeared Jonathon Baldwin, who made affidavit upon oath before me, that he had carefully examined Emma Baldwin, the alleged lunatic, and believes her to be an insane person, and, in the opinion of affiant, a fit subject for admission into a hospital for the insane. Thereupon I caused the said Emma Baldwin to be brought before me, and upon examination of Dr. Richard Jones, a licensed and reputable physician, a resident of this state, and Jonathon Baldwin, a member of the alleged lunatic's family and upon such examination of the alleged insane person, and the hearing of the testimony, I did decide that Emma Baldwin is insane, and it appearing that the said lunatic has a legal settlement in Randolph County, and that her being at large is injurious to herself

and disadvantageous if not dangerous to the community, and no becoming bond as the law directs, I did adjudge and direct that Emma Baldwin be committed to The State Hospital at Raleigh N.C., as a patient. Thereupon, I issued my warrant of commitment to the Sheriff of Randolph County, commanding him to take Emma Baldwin and convey Emma Baldwin to the proper Hospital, and there deliver Emma Baldwin to the Superintendent thereof for safekeeping.

Emma was admitted to The State Hospital at Raleigh (now known as Dorothea Dix Hospital) with a diagnosis of epilepsy. She remained there for three years, at which time she was discharged to her family in Randolph County. Five months later, she was readmitted to The State Hospital at Raleigh, where she lived for the next 44 years. Very few records from her stay in the hospital could be located; however, a mental health assessment from July 1979 indicated that her diagnoses were Organic Brain Syndrome secondary to epilepsy and severe mental retardation. Her medications at the time of the assessment were Dilantin, Mellaril, Cllace, Paladac, and Sustacal.

Upon discharge from Dorothea Dix Hospital on January 2, 1980, at 63 years of age, Emma was admitted to Randolph Rest Home. She was also admitted as a patient of Randolph County Mental Health Center on January 14, 1980. A mental health admission form from that date indicated that Emma was discharged from the hospital on no medication. The form also specifies the following:

Patient's behavior has been quite agitated since at Randolph Rest Home. She is not sleeping well at night, pacing the floor constantly all day, expresses a great deal of fear of dying of arthritis and wants to eat constantly. Patient has a history of epilepsy, but according to Ms. Wilson, Randolph Rest Home Operator, Dix informed her that Emma has not had a seizure in many years. She is on no medication for same. She has one sister in Seagrove who visited her at Dix in 1978. The patient will be on Medicaid. She does have a history of arthritis and only weighs 90 pounds at the present time but has a tremendous appetite. Patient

is not oriented to place, date or time. She is not suicidal, but creating a lot of noted agitation and problems in restlessness. Diagnosis is deferred at this time.

Emma continued to be followed by Randolph County Mental Health Center, and was seen every three months by a psychiatrist. In May 1983 her diagnosis had been changed to Major Depression. In late 1983, her diagnosis had changed again to Bipolar disorder. She was started on Lithium. A psychiatric note from June 1984 states the following:

Ms. Baldwin comes in alert, bright and cheerful, is doing better than I have ever seen her. She is much more verbal than usual. She was quite a delight to talk with. She has been steadily improving over the past few months and we talked about the trip that the group is going to take to Tweetsie Railroad this summer.

Emma continued to do well over the next few years, and her socialization skills continued to improve. In 1990, she was transferred to Brookstone Haven when Randolph Rest Home closed. In 1992 Emma began displaying aggressive behavior and was psychiatrically hospitalized at a community hospital. The hospital records indicate that she was in a “manic phase.” This hospitalization lasted less than two weeks and she was discharged back to Brookstone Haven. In 1994, Emma required another psychiatric hospitalization, this time at Dorothea Dix Hospital in Raleigh. She remained in the hospital for 10 days, and was once again discharged to Brookstone Haven. At the time of her discharge, her Bipolar diagnosis had been dropped, along with her medication for bipolar disorder, Lithium. Instead, she had a diagnosis of dementia. In 1995, Emma required yet another hospitalization at Dorothea Dix Hospital, where she remained for six months. Upon discharge she was once again taking Lithium for bipolar disorder. Instead

of returning to Brookstone Haven, Emma was admitted to a small group home in the same area, and operated by the same administrators who operated Brookstone Haven.

While living in the group home setting, Emma continued to display periodic inappropriate behavior; however, it was easier to intervene in the smaller setting. Emma also received case management from Randolph County Mental Health Center. One case management note from September 1996 states:

Discussed with staff Emma's alleged daughter. Informed them that Emma has explained this to myself and other staff and I am working on the situation. I informed them that at this point it has been a family secret and that her brother supposedly raised Emma's daughter and that at this point we do not even know if the daughter knows that Emma is her mother.

A case management note one month later states:

I called Emma's brother and he was adamant in stating that Emma did not, and it is not possible, that she had a daughter. He states that she did have a baby doll when she was in the assisted living facility and he feels that she is referring to the doll.

No additional notes related to a daughter were located in Emma's history.

In 1998, Emma required several hospitalizations as a result of recurrent pneumonia. A swallow study was conducted and it was determined that Emma was aspirating when she ate food. She was placed in a nursing home for rehabilitation and returned to the group home a few weeks later. Within a few weeks, she required another hospitalization for pneumonia. Her medical condition worsened, and she expired on July 21, 1998.



*This photograph was taken of Emma soon after she left Dorothea Dix Hospital. (Personal Family Photograph)*

**Figure 13. Emma—Soon after Leaving the Institution**



*This photograph was taken of Emma after she had been living in the community for several years. The babies are my nieces and nephew. (Personal Family Photograph)*

**Figure 14. Emma—Years after Living in the Community**



## **CHAPTER VIII**

### **CONCLUSIONS**

#### **Reflective Thoughts of Case Studies**

Each person who was included in this study was a unique individual who, in various ways, played an important role in my life. Nonetheless, I didn't know who they truly were until I delved into this study. It was easy for me to speak of growing up with older people who had mental illnesses, and talk about the uniqueness of that type of upbringing, but until I was able to put the pieces of the puzzles together, the puzzles that were their lives, I didn't realize how each of them had an effect on who I grew to be. The fact that I am now a mental health professional, and have had the opportunity to reflect on each of the people in this study, peruse their mental health records, and recall memories from my past, leads me to the conclusions that follow.

#### **Betsy**

I never knew the real Betsy. I knew a woman who had displayed behavior in her younger days that led the "professionals" to alter her brain in such a way that she would never be the same. I do not believe anyone intentionally harmed Betsy. There were no psychotropic medications at the time that could control her aggressive and delusional behavior, so the physicians did what was known as "best practice" at that time. If Betsy had continued to have these behaviors, it is very likely that she would have never left the walls of the institution. The altered Betsy that I knew was a woman who was gentle and

kind, and one who loved children. By having the opportunity to live in the same house with me, Betsy was finally able to experience maternal feelings. I believe that is why she always knew my name. I was the child she never bonded with when she was younger.

Betsy taught me what it meant to be responsible. While she was longing to be my mother, I was intent on ensuring her safety and wellbeing. By watching her to make sure she did not wander away, providing meals for her and administering her medication, I gained knowledge about taking care of people. Betsy also taught me to be compassionate. When I saw that she had a need, I wanted to make sure it was met. The lessons that I learned from her have been a blessing; however, to this day, I find myself worrying about the welfare of others, and trying to “fix” the problems of those around me, which is often a heavy burden to carry. Even so, I choose to look back on our relationship as one that helped me mature at an early age.

### **Sally**

I wish I could go back in time and “try again” with Sally. I believe that her epilepsy had a more significant effect on her behavior than anyone ever knew. I noted several instances in her medical record that mentioned seizure-type activity (staring, small movements, tremors, agitation, sleepiness), all of which could possibly be attributed to her seizure disorder. It would be interesting to know if the advances in the treatment of epilepsy that are available today would have made a difference in her moods and behaviors.

Additionally, from a mental health perspective, I am inclined to think that Sally would have reacted affirmatively to positive behavior interventions. It seems there were

two ways of dealing with Sally's behaviors; 1) giving in to her and letting her have whatever it was she wanted in order to prevent a "scene," and 2) reprimanding her for inappropriate actions. Had a positive behavior plan been implemented, one where she received age appropriate rewards for proper behavior, Sally may have learned to manage her anger more effectively. Most families have a member who can be hard to get along with. Sally was that person in our family. Although her behavior could be very challenging, Sally helped me look beyond her actions and focus on the cause of her actions, thereby becoming a more skilled mental health professional.

### **Simon**

Of all of the people I studied, Simon's story is the most unfortunate. Although I mentioned in the chapter on Simon that he was the first gay person I ever knew, after reading his mental health history, I believe he was the first transgendered person I ever knew. It does appear that there were delusions that were present throughout his life, but it is difficult to ascertain if those delusions were manifested because of the anxiety and depression he suffered from attempting to cope with his belief that he was a woman in a man's body, or if they were unrelated. Regardless, if Simon had been born 40 years later, he could have been treated in a community mental health setting versus being institutionalized for the majority of his adult life. He also could have been educated on gender reassignment. Instead, he was forced to undergo a lobotomy. Simon's mental health records indicate that he endured broken bones while in the institution. There are also sections that mention beatings he suffered at the hands of other male patients. Were these beatings the result of his feminine mannerisms, or his persistent discussions of

being a woman? No one will ever know. I will always wish that I had had a better understanding of people who are transgendered. Maybe I could have been that person that could have listened to Simon when he felt the need to discuss his feelings. Unfortunately, no one in his life understood those feelings. At any rate, Simon was the first person in my life to teach me to be tolerant and accepting of differences in others.

### **Emma**

Like Sally, Emma's seizure disorder at an early age played a significant role in her future. Because of her epilepsy, she lived the majority of her life in an institution. Had treatment been available in the community, Emma could have lived a very productive life. When she was discharged from Dorothea Dix Hospital in 1980, the Emma that we saw displayed typical institutional behavior. She could not sit for long periods of time, had hand movements/rituals, ate all of her meals rapidly, as if someone would steal her food, and had difficulty carrying on a conversation. Over the years, these institutional behaviors diminished tremendously. Before her death, she was going on vacations, eating out, conversing about her likes and dislikes, and establishing long lasting relationships. She became an individual that everyone loved and enjoyed being around.

Emma taught me what it meant to be loved. She was very affectionate, often offering a hug and a kiss on the cheek to those she loved. She also taught me about honesty. If she did not like someone or something, you knew it. She made it plain. One of Emma's sayings when she didn't like something was, "I wouldn't have it off a Christmas tree." Another of Emma's aphorisms was, "That's a lie of the devil." This was used when

someone made a statement that she considered untrue. I use both of these sayings to this day. It's my homage to Emma.

### **Final Thoughts**

What is the meaning of “normal”? As I attempted to conduct a scholarly search for a definition, I found that it is easier to pinpoint a description of “abnormal.” The *Diagnostic and Statistical Manual of Mental Disorders* (DSM), which catalogs all psychiatric diagnoses and is regularly used by mental health clinicians, provides a wealth of information related to what is abnormal; however, a search for the term “normal personality” reveals no results (Mosak, 1991). Social constructionists argue that the DSM-IV offers positions on normality that come from an elitist perspective and provide stereotypical impressions of race, gender and sexuality (Cermele, 2001). Wood (2007) suggests that the normality-as-mental-health perspective describes normal by use of the negative: “Normal people are those who are not mentally ill.” The process of labeling an individual as abnormal has negative outcomes, and places the problem within the person, which “shifts the power to determine normality from the individual to the mental health professional” (Caplan, 1995).

In addition to using the DSM as a way to categorize people and their illnesses, physicians and clinicians often use the “medical model” to plan a strategy for treatment once a diagnosis has been made. The medical model emphasizes an individual's illness by using a biological approach. The person presents with a problem, which is identified by the physician, a diagnosis is attached, and the physician prescribes treatment. As early as the 1960s, the medical model was criticized for its paternalistic foundation (Shah,

2007). Various advocates for people with disabilities believe that the medical model emphasizes the individual as the problem, and concentrates on what an individual *cannot* do rather than on his/her strengths and abilities (Shah, 2007). Further, professional literature illustrates the power that is amassed by physicians due to their knowledge about illnesses, and the matching defenselessness of “clients” that is created due to their *lack* of knowledge (Weick, 1983). Weick illustrates the angst individuals may experience when participating in treatment that is driven by the medical model.

It should be remembered that the medical model is deeply rooted in notions of individual fault and deficiency. Although people have ostensibly moved away from archaic convictions with regard to mental and physical illness as signs of divine retribution, there are still remnants of guilt when one’s body or mind falls from perfect (Weick, 1983).

Although the first edition of the DSM was published in 1952 (Reid, 1995), my parents did not know that such a manual existed when they moved to the county home. Similarly, they were not familiar with the medical model, or any other model for that matter. They never referred to a handbook for guidance on how to live and work with people with mental illness and those who were aging. Nor did they receive formal training related to providing appropriate supports for these groups of people. A disruption of normal began as they simply did what came natural. Although they were not conscious of it, they had started to blur the boundaries between client and caretaker, and more importantly, between normal and abnormal. They treated the “inmates” as they would any other person living in the household, and an atmosphere of social inclusion was formed in a setting where it had never been present. The people who lived at the county

home played games with the children, cooked meals with my mother and tended the farm with my father. Everyone shared the joy when babies were born, and collectively mourned the loss when an old friend passed away. People who had previously been labeled as idiotic and feeble-minded acquired a sense of belonging, and a new family was formed.

My parents set a standard of practice for us to follow as we became adults. Our agency, Therapeutic Alternatives, currently provides direct services for more than 1,000 people, and employs over 700. While it is not possible for us to operate exactly as my parents did in the 1950, 60s, and 70s, we strive to apply the person-centered approach that they implemented. Interestingly, current models of practice in mental health and aging are beginning to illustrate person-centeredness and inclusion as best practices. Recently, our agency was accredited by a nationally recognized accrediting entity and it was quite clear from their standards that best practice for those with mental illnesses and/or developmental disabilities involves extensive efforts to be inclusive and person-centered, disrupting the medical model and calling into question the concept of the binary of normal/abnormal. As we move forward with this philosophy, it is important that we ask ourselves a question. *Why can we effortlessly recognize what is abnormal, and those who are abnormal, but rarely see ourselves as members of that category?* Each person has a story with good and bad elements. If we take time to listen closely to these stories, we uncover features that sound familiar... hints of ourselves, and a connection to other people that sends us down a path where we eventually understand that “normal” may not really exist. Thus, our concepts of ourselves within a “normal” space become blurred and

we are able to begin to cross some of the boundaries that have been rigid, as we move into spaces of existence that allow for pluralistic notions of what we *are* and *are not*.

Throughout this study, as I reflected on memories and gained knowledge from mental health records, the biographical, autobiographical and historical information overlapped and intersected. My life experiences, through historical and personal perspectives, have played significant roles in establishing my belief system and in defining me as an individual. Specifically, my experiences with people who essentially became members of my family have helped to mold me, for better or for worse, into the person I am today.

Richardson and St. Pierce (2005) state, “None of us knows his or her final destination, but all of us can know about the shape makers of our lives that we can choose to confront, embrace, or ignore.” I have chosen to embrace those shape makers whom I consider to have made my life richer. Without knowing they did so, they helped me to have a better understanding of the complexities of the world around me.





*The county home as it stands today. (Personal Family Photograph)*

**Figure 15. *The Randolph County Home as it Appears Today***

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